

RACIAL AND SOCIOECONOMIC DIFFERENCES IN ORGAN DONATION
AND ACCESS TO SOLID ORGAN TRANSPLANTATION

by
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ABSTRACT

Solid organ transplantation, a curative healthcare intervention for patients with end-stage disease of the liver or kidney, precipitates fervent discourse around supply, from who are deceased donor organs recovered, and demand, to who receives scarce deceased donor organs. Social justice principles are inherent to this discourse, and it is the vocation of public health research to monitor health inequalities, which are unjust differences in health according to social hierarchies. Using population-level registry, mortality, and census-based data, this dissertation examines racial and socioeconomic differences in organ donation and access to the transplant waiting list.

First, we use Centers for Disease Control and Prevention mortality data to examine racial differences in organ donation over time in the United States (Chapter 2). We found that differences in deceased organ donation between the White population and some racial minority populations have attenuated over time, and that the greatest gains in donation were observed among the Black population.

Second, we use national, transplant registry data linked to American Community Survey data to examine the relationship between multidimensional socioeconomic status, race, and biologic relationship to the recipient (Chapter 3). We found that that socioeconomic status uniquely varies according to race and biologic relationship to the recipient among the Black population, with Black, related donors having lower socioeconomic status than Black, unrelated donors, and the lowest socioeconomic status of all race and relationship combinations in the living kidney donor population.

Third, we examine the influence of expanding Medicaid, a social protection policy that was intended to improve healthcare access for low-income and racial minority populations, on waitlisting for kidney transplant (Chapter 4). We found that while Medicaid expansion was associated with increases in kidney transplant waitlist registrations, increases varied across sociodemographic groups.

Finally, in a perspective, we reflect on learning to study “race” during our doctoral studies (Chapter 5). We advocate for the routine application of social epidemiologic theory to racial disparities research, increased use of analytic approaches that move beyond describing racial differences as we have, and peer review by surgeon scientists who have social epidemiologic expertise and training.

This dissertation demonstrates findings and limitations of big data in organ transplantation research that uses national, transplant registry and public health data sources to examine health inequalities. Our hope is that this dissertation will be used by the transplant community to pause, re-direct resources, collect better data, and conduct population health research that can be used to address health inequalities along social hierarchies in solid organ transplantation.

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- Amber

QUOTES

I, Too

By Langston Hughes¹

I, too, sing America.

I am the darker brother.

They send me to eat in the kitchen

When company comes,

But I laugh,

And eat well,

And grow strong.

Tomorrow,

I'll be at the table

When company comes.

Nobody'll dare

Say to me,

"Eat in the kitchen,"

Then.

Besides.

They'll see how beautiful I am

And be ashamed—

I, too, am America.

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Chapter 1. Introduction

Solid organ transplantation, a curative healthcare intervention for patients with end-stage disease of the liver or kidney, precipitates fervent discourse around supply, from who are deceased donor organs recovered, and demand, to who receives scarce deceased donor organs. Social justice principles are inherent to this discourse, and it is the vocation of public health research to monitor health inequalities,² which are unjust differences in health according to social hierarchies.

In the United States, racism and socioeconomic status create a social hierarchy, or system of stratification and organization of individuals according to social constructs.³⁻⁵ Fundamental Cause Theory is a social epidemiologic theory that explains how “fundamental causes” of disease determine allocation resources that that have an effect on disease along social hierarchies.⁶⁻⁸ Specifically, examples of “fundamental causes” that dictate access to resources include money, knowledge, power, prestige, social support, social networks. These resources can be used to avoid and/or lessen disease.

In this dissertation, “fundamental causes”, race/racism and socioeconomic status, are the main covariates, and the overarching theme of this dissertation is health inequalities in organ transplantation according to these social status variables. Race (i.e., racism) is a Western societal ideal that has its parentage in the development of countries (i.e. geographic units of individuals of similar ethnicities), colonialization of the Native American population in what we now call the United States, and slavery.⁹ During this time, racial classification was developed to justify exploitation and barbaric treatment of social groups who were deemed inferior by the social group in power.^{9,10} Following these

historic events, race has persisted through time to fill a social need of capital accumulation and concentration of power, and has been cultivated in the institutions, and hearts, minds and behaviors of Americans. Race is routinely used in public health research without considering its origins, definition or measurement.¹¹⁻¹⁵ Race is a social construct that is based on physical characteristics, and dictates distribution of risks and opportunities in a racialized society.¹⁶ When we study “race” in public health research, we are essentially studying the experience of “racism” in the United States.

“Race/Racism” is theoretically linked to socioeconomic status, which is a multi-dimensional construct that includes income, wealth, education and occupation. Similar to “race”, socioeconomic status reflects position within a social hierarchy.^{17,18} Income is a direct measure of material resources that can be converted into health promoting assets. Wealth is an individual’s total accumulated economic resources, which can be used to buffer temporary income declines. Education is a determinant of employment and income and can influence cognition, literacy and communication. Lastly, occupation reflects social standing. Individual dimensions are moderately correlated and have unique effects on health.¹⁹ Further, while there is a gradient of health according to socioeconomic status, racial non-equivalence leads to differences in the effect gradient across racial groups.²⁰ Health inequalities research often starts with “race” and “socioeconomic status” stratification.

Recently, medicine has started to grapple with the legacy of slavery within medicine, and the propagation of “scientific racism” in public health research. This dissertation tackles two topic areas in organ transplantation that have been historically “racialized” – organ donation and living kidney donor outcomes – and ends with an examination of a social protection policy intended to improve the health of low-income adults and racial

minorities. In Chapter 2, we examine racial differences in deceased organ donation over time in the United States. In Chapter 3, we examine the relationship between multidimensional socioeconomic status, race and biologic relationship among living kidney donors. In Chapter 4, we examine the influence of Medicaid expansion on kidney transplant waitlist registrations across strata of race, income and age. In Chapter 5, we reflect on the scholarship of “race” and suggestions for our peers undertaking racial disparities research in the surgical sciences. While the topic areas are not novel, this dissertation integrates the above social epidemiologic theory and concepts to provide new insights and interpretations of historic assumptions.

Chapter 2. Racial and Ethnic Differences in Deceased Organ Donation Ratio over Time in the United States

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Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2017 on CDC WONDER Online Database released December 2018. Data are from the Multiple Cause of Death Files, 1999-2017, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/ucd-icd10.html>.

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KEY POINTS

Question:

How has deceased organ donation by race and ethnicity changed over time in the United States?

Findings:

Between 1999-2017, the greatest increases in donation ratios (actual deceased donors to potential donors) were seen in Blacks and American Indian/Alaska Natives. While these increases attenuated racial differences, Blacks and American Indian/Alaska Natives still donate at 69% and 28% the rate of Whites. Interestingly, ethnic differences have increased over time, with Hispanic/Latinos having a 4% lower donation ratio than non-Hispanic/Latinos.

Meaning:

Though deceased organ donation among some racial groups increased over time at a faster rate than Whites, racial differences remain substantial.

ABSTRACT

Importance:

Historically, deceased organ donation was lower among Blacks compared to Whites, motivating a number of efforts to reduce racial disparities. The overarching impact of these efforts in Black and other racial/ethnic groups remains unclear.

Objective:

To examine changes in deceased organ donation over time

Design:

Observational cohort study

Setting:

Population-based

Participants:

We studied data between 1999-2017 from the Scientific Registry of Transplant Recipients to quantify the number of actual deceased organ donors, and from the Centers for Disease Control and Prevention Wide-ranging Online Data for Epidemiologic Research Detailed Mortality File to quantify the number of potential donors (individuals who died under conditions consistent with organ donation).

Exposures:

Race and ethnicity

Main outcome and measure:

For each racial/ethnic group and year, we calculated a donation ratio as the number of actual deceased donors divided by number of potential donors. We used direct age- and sex-standardization to allow for group comparisons, and Poisson regression to quantify donation ratio changes over time.

Results:

Among Blacks, the donation ratio increased 2.58-fold between 1999-2017. This increase was significantly greater than the 1.60-fold increase seen in Whites (yearly change in adjusted incidence rate ratio (aIRR): Black 1.05 [95% CI, 1.05 – 1.05, $p < 0.001$]).

Nevertheless, substantial racial differences remained, with Blacks still donating at only 69% the rate of Whites in 2017 ($p < 0.001$). Among other racial minorities, there were less drastic changes. Deceased organ donation increased 1.80-fold among American Indian/Alaska Natives and 1.40-fold among Asians or Pacific Islanders, with substantial racial differences remaining in 2017 (American Indian/Alaska Natives donating at 28% and Asian/Pacific Islanders donating at 85% the rate of Whites). Interestingly, deceased organ donation differences between Hispanic/Latinos and non-Hispanic/Latinos increased over time (4% lower in 2017).

Conclusions and Relevance:

Differences in deceased organ donation between Whites and some racial minorities have attenuated over time. The greatest gains were observed among Blacks who have been the primary targets of study and intervention. Despite improvements, substantial differences remain, suggesting that novel approaches are needed to understand and address relatively lower deceased organ donation among all racial minorities.

INTRODUCTION

Historically, in the United States, deceased organ donation among all racial/ethnic minorities was lower than that of Whites.²¹⁻²⁴ In the 1990s, the most common deceased organ donor was a White male between 18 and 34 years of age,²⁵ and less than 32% of deceased donor organs came from racial/ethnic minorities.²⁶

Relatively lower rates of deceased organ donation from minorities not only impacts the general supply of organs for transplantation but has important implications on long-standing racial disparities among waitlisted candidates. For example, waitlisted candidates with blood type B, who are mostly racial/ethnic minorities,²⁷ have the longest wait times and receive fewer transplants than candidates with other blood types.²⁸ Similar scenarios are seen in organs where HLA matching (which is correlated with race) is an allocation priority.²⁹⁻³² Thus, increasing minority representation in the deceased donor pool is particularly relevant for minorities on the waitlist.

Over time, the transplant community has designed a number of interventions to address relatively lower deceased organ donation among racial/ethnic minorities.³³⁻⁵¹ These interventions have incorporated culturally appropriate messaging,⁴⁷ story-telling approaches,⁵⁰ emphasis on personal connections and recognizable persons, and use of community workers, community-based organizations and social networks with the intent of modifying knowledge, attitudes and donor registration and consent behaviors. In-hospital setting interventions have adopted race and gender concordant teams to optimize family approach practice.^{52,53} However, the overarching impact of these efforts remains unclear.

Therefore, the goal of this study was to quantify how deceased organ donation among racial/ethnic groups has changed over time in the United States at the population-level. We used publicly available, national mortality and transplant registry data to (i) define a reliable, comparable denominator of potential organ donors; (ii) define a donation ratio as the number of actual donors divided by the number of potential donors; (iii) quantify donation ratio changes within racial/ethnic groups over time; and (iv) compare donation ratios between racial/ethnic groups.

METHODS

Data Sources

We used data from the Centers for Disease Control (CDC) and Prevention Wide-ranging Online Data for Epidemiologic Research (WONDER) and the Scientific Registry of Transplant Recipients (SRTR). CDC WONDER is an online resource that includes over 20 collections of public-use data related to public health that is submitted by state and local health departments, the Public Health Service, and the academic public health community. The Detailed Mortality File collection includes death counts and a single underlying cause of each death from death certificates at census regions, state, and county-levels. The Detailed Mortality File also includes place of death (i.e. inpatient medical facility, outpatient medical facility or emergency room, home, hospice, or long-term care facility), and month and weekday of death.

The SRTR data system includes data on all donor, wait-listed candidates, and transplant recipients in the US, submitted by the members of the Organ Procurement and Transplantation Network (OPTN). The Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services provides oversight to the

activities of the OPTN and SRTR contractors. Details of these data has been described elsewhere.⁵⁴

This study was a secondary analysis of deidentified data and was classified as exempt and not human subjects research by the Institutional Review Board of Johns Hopkins University (NA_00042871).

Study Population

We used CDC Detailed Mortality File (1999-2017) to study inpatient medical facility deaths that could have been organ donors. Given that the definition of a death eligible for donation varies across organ type and over time, we defined a universal definition of eligible death as being between 1-76 years old, and not having an underlying cause of death due to infection or malignant and in situ neoplasms. To identify potential donors, we used the *International Classification of Diseases* (ICD), Tenth Revision Cause-of-Death codes to exclude the following non-eligible deaths according to OPTN criteria: bacterial, viral, fungal, parasitic, and prion infections (*International Classification of Diseases, Tenth Revision* codes A00-B99). We also excluded deaths due to malignant and in situ neoplasms (C00-D09), polycythemia vera (D45), myelodysplastic syndromes (D46), neoplasms of uncertain or unknown behavior (D47-D48), aplastic and other anemias (D60 – D64), agranulocytosis (D70), functional disorders of the polymorphonuclear neutrophils (D71), and other disorders of white blood cells (D72). After applying OPTN exclusion criteria, the population remaining constituted potential organ donors. We then used SRTR data on organs recovered to ascertain the actual number of deceased organ donors. Organ types included kidney, heart, lung, and liver, and actual deceased organ donors were counted only once in the case of multiple recovered organs from one donor.

Classification of Race and Ethnicity

We defined race and ethnicity according to the Office of Management and Budget 1997 Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, which includes Non-Hispanic White, Non-Hispanic Black or African American, Asian or Pacific Islander, and American Indian or Alaska Native, and Hispanic/Latino ethnicity categories.

Donation Ratio

We defined the donation ratio as the absolute number of deceased donors (using SRTR data) divided by the number of eligible deaths (using CDC WONDER data). For each year and racial and ethnic group, we calculated the crude donation ratio. To account for differences in the age distribution of death between racial/ethnic groups, we also calculated adjusted (standardized) donation ratios using direct standardization for age of death (stratified in decades) and sex. In order to understand how donation changed over time, we used modified Poisson regression, adjusting for age, sex and race. Analyses that were stratified by racial and ethnic groups were adjusted for age and sex only.

Sensitivity Analyses

To explore differences in eligible death definitions across organ types and over time, we applied additional, unique exclusion criteria to our universal definition of eligible death according to organ type. For kidney, we excluded inpatient deaths with underlying causes of death due to glomerular diseases (N00-N07), chronic renal failure and end-stage renal disease (N18), and congenital malformations of the urinary system (Q60-Q64). For heart/lung, we excluded deaths greater than 60 years old and due to hypertensive disease (I10-I15), ischemic heart disease (I20-I25), myocarditis (I40),

cardiomyopathy (I42), influenza and pneumonia (J09-J18), and chronic lower respiratory disease (J40-J47). For liver, we excluded deaths due to liver disease (K70-K76). For contemporary policies allowing for donation from donors with HIV and viral hepatitis, we limited the study period to 2014-2017 and excluded underlying causes of death due to bacterial, viral, fungal, parasitic, and prion infections (*ICD* codes A00-B99) with the exception of HIV (B20-B24) and viral hepatitis (B15-B19).

Statistical Analysis

All analyses were performed using Stata 16.0/MP for Linux (College Station, Texas), with $p < 0.05$ considered statistically significant.

RESULTS

Overall temporal trends

The overall standardized donation ratio increased from 1.96% in 1999 to 3.33% in 2017 (**Figure 1**). This translated into a 3% increase per year across the study period (adjusted incidence rate ratio [aIRR]= 1.03 [95% CI: 1.02 – 1.03], $p < 0.001$).

Temporal trends by race

The trends varied across racial groups. For Whites, the standardized donation ratio increased from 2.29% in 1999 to 3.66% in 2017 (**Figure 2**), an overall 1.60-fold increase, or a 3% increase per year across the study period (aIRR=1.03 [95% CI, 1.02 – 1.03], $p < 0.001$) (**Table 1**). For Blacks, the standardized donation ratio increased from 0.87% to 2.23%, an overall 2.58-fold increase, or a 5% increase per year (aIRR= 1.05 [95% CI, 1.05 – 1.05, $p < 0.001$). This increase over time was significantly higher than the increase over time in Whites ($p < 0.001$). For American Indians or Alaska Natives, the

standardized donation ratio increased from 0.65% to 1.17%, an overall 1.80-fold increase, which translated into a 3% increase per year (aIRR=1.05 [95% CI, 1.03 – 1.06, $p<0.001$). This increase over time was also significantly higher than the increase over time in Whites ($p=0.007$). For Asians or Pacific Islanders, the standardized donation ratio increased from 2.24% to 3.13%, an overall 1.40-fold increase, or a 2% increase per year (aIRR= 1.02 [95% CI, 1.02 – 1.03], $p<0.001$). This yearly change was similar to yearly changes for Whites ($p=0.60$).

Temporal trends by ethnicity

The trends also varied by ethnicity. For non-Hispanic/Latinos, the standardized donation ratio increased from 1.97% in 1999 to 3.45% in 2017 (**Figure 3**), an overall 1.70-fold increase, or a 3% increase per year across the study period (aIRR= 1.03 [95%CI 1.03 – 1.03], $p<0.001$) (**Table 1**). For Hispanic/Latinos, the standardized donation ratio increased from 1.92% to 3.35%, a 1.93-fold increase, or a 3% increase per year (aIRR=1.03 [95%CI 1.03 – 1.03], $p<0.001$). This increase over time was not significantly different than the increase seen in non-Hispanic/Latinos ($p=0.17$).

Differences according to race and ethnicity

In 1999, Asian or Pacific Islander, Blacks and American Indians/Alaska Natives donated at 80%, 46% and 20% the rate of Whites (**Table 1**). Interestingly, Hispanic/Latinos donation rates were not significantly different than Non-Hispanic/Latinos. In 2017, racial differences attenuated, but remained substantial: Asian or Pacific Islanders, Blacks, and American Indians/Alaska Natives donated at 85%, 69%, and 28% the rate of Whites (**Table 1**). Different than 1999, Hispanic/Latinos donation rates were 4% lower than Non-Hispanic/Latinos in 2017.

Sensitivity Analysis

Trends over time and differences in the standardized donation rates between Whites and racial and ethnic minorities were similar when using different eligible death definitions specific to kidney, liver, and heart/lung (**Table 2**). When including potential donors with underlying causes of death due to HIV or viral hepatitis, the yearly increase in the standardized donation ratio between 2014 and 2017 was greatest for American Indians and Alaska Natives (aIRR=1.08 [95%CI 0.96 – 1.22], $p<0.001$) and Whites (aIRR=1.03 [95%CI 1.02 – 1.05], $p<0.001$) (**eTable4**).

DISCUSSION

Using national mortality and transplant registry data, we found that increases in organ donation over time were greater among Blacks (2.58-fold between 1999-2017) and American Indians/Alaska Natives (1.80-fold) as compared to Whites (1.60-fold). Despite these changes, racial differences remained, with Blacks and American Indians/Alaska Natives donating at 69% and 28% the rate of their White counterparts. We found that ethnic differences increased over time, with Hispanic/Latinos having a 4% lower deceased organ donation rates relative to Non-Hispanic/Latinos in 2017.

Our findings of relatively lower donation rates among minorities are consistent with prior studies in solid organ transplantation^{21,28,55-60} and mirror racial differences seen in blood,⁶¹ hematopoietic stem cell⁶² and biospecimen donation.⁶³ However, we have shown that at least these differences are attenuating, with much higher gains in organ donation among Blacks than other racial groups.

We found that American Indian/Alaska Natives and Asian or Pacific Islanders also have lower deceased organ donation rates relative to Whites, and less improvement in donation rates was appreciated over time in these racial subgroups. This is especially important since the mortality rates and consequent potential pool for deceased donor organs have increased among American Indian/Alaska Natives over time.⁶⁴ While there is a preponderance of studies of Black subjects, donation practices and donation-related beliefs of American Indians/Alaska Natives and Asian or Pacific Islanders are less often studied and infrequently reported at the population-level. American Indians are less likely than Whites to be registered as organ donors⁶⁵ and described mechanisms have been similar to those of Blacks. In prior studies, relatively lower deceased organ donation among racial minorities has been attributed to religious affiliation,^{46,65,66} desire for bodily integrity at death,^{67,68} medical mistrust,⁶⁹ skepticism about healthcare provider motivations and clinical management of dying patients, and fear of organ misuse and inequitable allocation of organs.^{67,70} The consistency of the relationship between race and deceased organ donation over time, and the risk factor similarity across racial groups might be reflective of marginalized status rather than inherent beliefs particular to a social group.

Our results indicate that despite research and intervention attempts, minimization of racial differences at the population-level have not been fully realized. The Organ Donation Breakthrough Collaborative, the largest scale intervention designed to increase deceased organ donation in 2003, was mostly effective in increasing donor consent rates for non-Hispanic Whites in reported locations.^{71,72} The intervention provided training on best practices drawn from Organ Procurement Organizations (OPOs) and hospitals with donor conversation rates upwards of 75% and included clinical triggers that allowed for more timely identification of potential donors, early referral, increased

family coordinator resources, integrated process measurement, and establishment of oversight committees.^{71,73,74} In contrast, smaller scale, community-driven interventions have been effective in increasing organ donation among Blacks^{35-37,39,75} and our population-level approach is likely masking these smaller geographic unit-level successes. Our findings suggest that these successful efforts might need to be scaled up, funded, and widely disseminated to produce population-level change.

For most of our study period, we found that donation rates were similar between Hispanic/Latinos and Non-Hispanic/Latinos, which is a novel finding that might be explained by our ethnicity definition and standardization methodology. Our ethnicity category included potential donors of any race (i.e. Hispanic/Latinos could be Black, White, Asian or Pacific Islander, or American Indian/Alaska Native), unlike many previous studies that grouped race and ethnicity together (i.e. White, Black, Hispanic/Latino, etc., as separate categories). Our number of actual deceased donors and ethnic difference in 2017 are consistent with prior studies reporting higher donation rates in Non-Hispanic/Latinos relative to Hispanic/Latinos.^{56,76} It might also be that accounting for the age and sex distribution of mortality between ethnic groups is highly informative. Other studies have found more granular components of ethnicity, such as acculturation, to be related to organ donation.⁷⁷ Acculturation, among other ethnicity-related factors,¹² such as immigration status or country of origin,⁷⁸⁻⁸⁰ which we are unable to capture with our data sources, might prove to be informative in explaining heterogeneity in findings across published studies.

Our findings that substantial racial differences in organ donation remain, even after many concerted efforts, suggest that perhaps novel approaches are needed to address racial/ethnic differences in deceased organ donation. Historically, research has been

focused on understanding presumed inherent minority attitudes and beliefs regarding donation,^{81,82} with resultant interventions that are mostly donor and donor-family centric level intended to modify individual behavior.^{43,45,47,82,83} As compared to empirical research into individual-level factors, a robust contextual understanding is largely missing. Many health disparities researchers and theoretical experts have advocated for a shift away from research solely focused on individual behaviors when seeking to address racial disparities in health,^{84,85} as racial disparities are most often explained by differential treatment, opportunity, and access to knowledge and resources to maintain and improve health.^{6,7,84,86,87} There is a small research base that has identified factors unrelated to potential donor and donor family knowledge, beliefs and behavior. After accounting for race, contextual risk factors related to geography, such as concentrated disadvantage, socioeconomic deprivation, and residential segregation, have been found to be associated with organ donation.⁸⁸⁻⁹⁰ Requestor communication skills and interpersonal interactions with families have been found to partly explain geographic differences in donor authorization,⁹¹ which vary widely across geographies in the US.⁹² Requestor behaviors also vary across race, with White families more often being approached for donation consent than Black families irrespective of setting and cause of death.⁹³ Among Black families approached for donation, those who refuse more often report feeling pressured and having low quality discussions with requestors, but have similar attitudes towards donation as families who authorize donation.⁹⁴ Donor family management and communication quality, among other steps of the donor authorization and recovery process, remain unchecked, and when evaluated demonstrate reporting inaccuracies.^{95,96} Further, current publicly reported data at the population-level does not support this lens of empirical research.⁹⁷

Our work is not without limitations. The CDC Detailed Mortality File includes data based on death certificates, which have a single underlying cause of death for each US resident.⁹⁸ Therefore, it is possible that potential donors who met our eligible death definitions had contraindications to donation that were not the documented underlying cause of death, resulting in an overestimation of potential donors. Similarly, we are unable to determine whether donors met brain or cardiac death criteria for donation, which if known, would make our potential donor pool smaller. The overestimation of potential donors is unlikely to threaten our inference, given that our definitions were not differentially applied across racial/ethnic groups. We used OMB standards for race/ethnicity categorization, which have become less precise as the US has become increasingly more diverse.⁹⁹ A different racial/ethnic categorization scheme might produce different inference and misclassification of racial assignment may also be masking more relevant distinguishing characteristics associated with donation. Further, while federal OMB standards guide us in data presentation at the practical level, race is socially assigned,^{11,16,100,101} and we are unable to capture the influence of the real-life social assignment on deceased organ donation. While our national mortality data lacks granularity such as ventilation or severe sepsis, concordance is high between donation rates calculated using these data compared to more granular state data (Pearson correlation coefficient = 0.97).¹⁰² Therefore, our inability to account for these nuances in national mortality data is unlikely to threaten our conclusions.

A strength of our study is that we have used publicly available national mortality data to create a denominator of potential donors that is comparable across racial/ethnic groups and through time. Currently, the numbers of potential donors in defined geographic units across the US are obtained by self-report from OPOs, and OPO performance comparisons using potential deaths has been regarded as being unverifiable and

inaccurate.^{95,96,103} As a result, the Centers for Medicare and Medicaid Services is considering other data sources,¹⁰⁴ such as national mortality data based on death certificates, to standardize potential donor pool ascertainment across OPOs.

In this 18-year national study, we found that deceased organ donation among some racial groups increased over time at a faster rate than among Whites, but differences between Whites and all racial minority groups remained. Our findings suggest that novel approaches are likely needed to understand and address relatively lower deceased organ donation among all racial minorities.

Figure 1. Overall Age- and Sex-Standardized Deceased Organ Donation Rate from 1999 to 2017

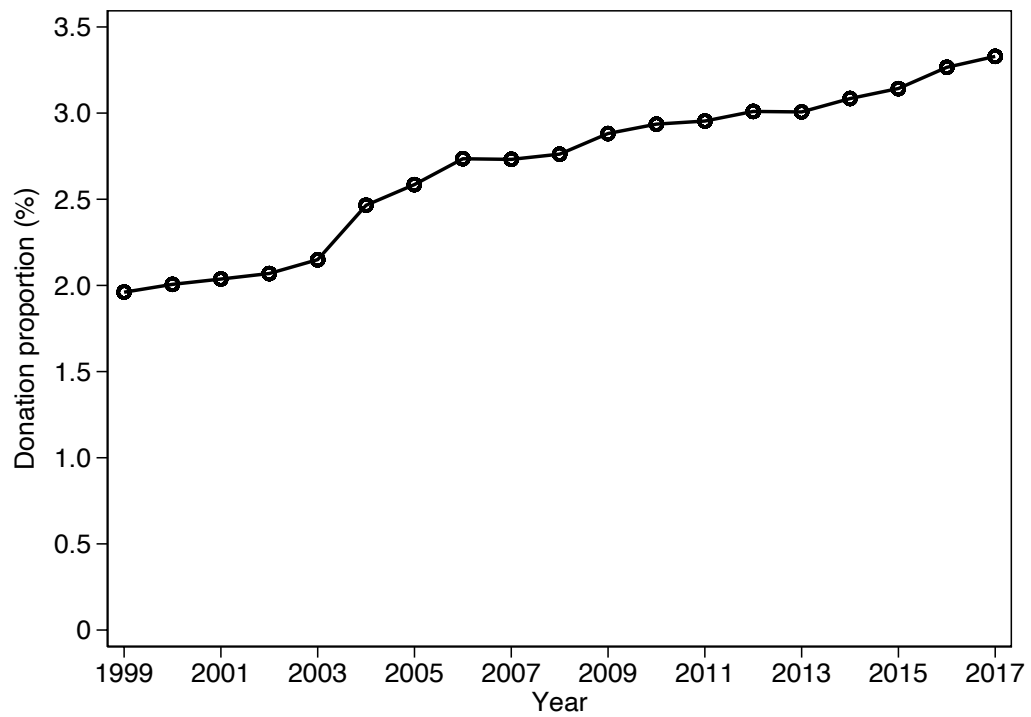


Figure 2. Age- and Sex-Standardized Deceased Organ Donation Rate by Race from 1999 to 2017

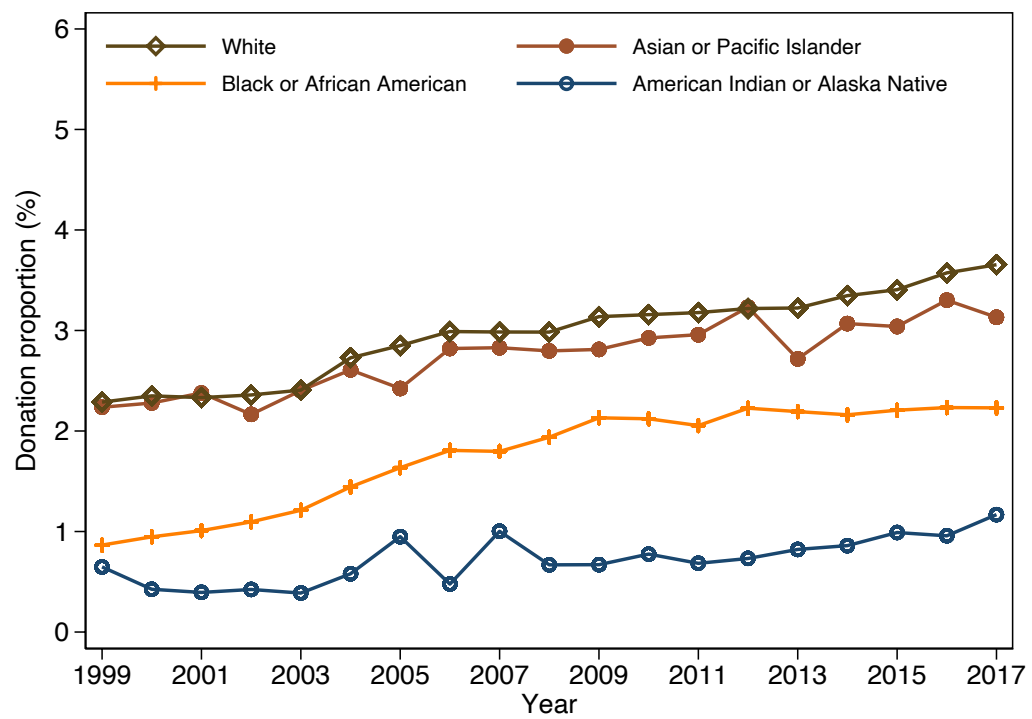


Figure 3. Age- and Sex-Standardized Deceased Organ Donation Ratio by Ethnicity from 1999 to 2017

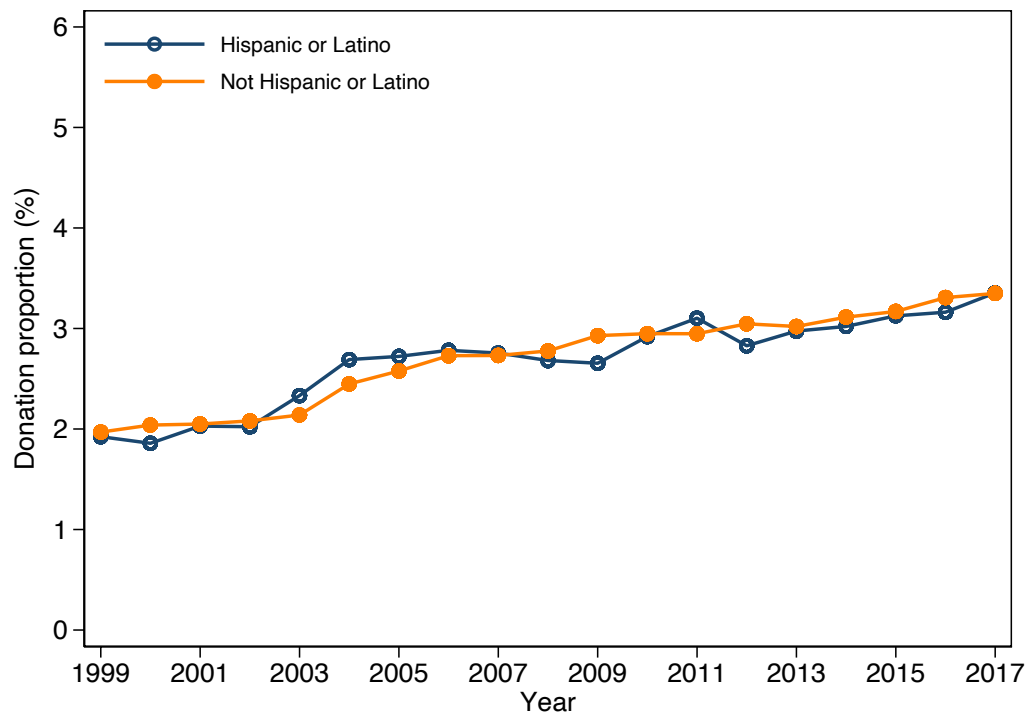


Table 1. Age and Sex-Standardized Incidence Rate Ratio of Donation in 1999 and 2017

	1999	2017	Yearly Increase
	aIRR (95% CI)	aIRR (95% CI)	aIRR (95% CI)
Non-Hispanic White	Reference	Reference	1.03 (1.02 – 1.03)
Black	0.46 (0.45 – 0.47)	0.69 (0.67 – 0.70)	1.05 (1.05 – 1.05)
Asian or Pacific Islander	0.88 (0.82 – 0.94)	0.85 (0.81 – 0.90)	1.02 (1.02 – 1.03)
American Indian or Alaska Native	0.20 (0.17 – 0.24)	0.28 (0.25 – 0.32)	1.05 (1.03 – 1.06)
Non-Hispanic/Latino	Reference	Reference	1.03 (1.02 – 1.04)
Hispanic/Latino	0.99 (0.96 – 1.02)	0.96 (0.93 – 0.98)	1.03 (1.02 – 1.03)
Abbreviation: aIRR, adjusted incidence rate ratio; CI, confidence interval.			

Table 2. Age and Sex-Standardized Incidence Rate Ratio of Donation in 1999 and 2017 Stratified by Organ Type

Organ Type	1999 aIRR (95% CI)	2017 aIRR (95% CI)	Yearly Increase aIRR (95% CI)
Kidney			
Non-Hispanic White	Reference	Reference	1.03 (1.03 - 1.03)
Black	0.43 (0.42 - 0.44)	0.63 (0.62 - 0.65)	1.05 (1.05 - 1.05)
Asian or Pacific Islander	0.85 (0.79 - 0.92)	0.86 (0.81 - 0.91)	1.03 (1.02 - 1.03)
American Indian or Alaska Native	0.20 (0.17 - 0.24)	0.29 (0.25 - 0.32)	1.05 (1.03 - 1.06)
Non-Hispanic/Latino	Reference	Reference	1.03 (1.03 - 1.03)
Hispanic/Latino	0.97 (0.94 - 1.00)	0.96 (0.94 - 0.99)	1.03 (1.03 - 1.03)
Liver			
Non-Hispanic White	Reference	Reference	1.02 (1.02 - 1.02)
Black	0.44 (0.43 - 0.45)	0.70 (0.69 - 0.72)	1.05 (1.05 - 1.05)
Asian or Pacific Islander	0.80 (0.75 - 0.87)	0.84 (0.79 - 0.89)	1.03 (1.02 - 1.03)
American Indian or Alaska Native	0.21 (0.18 - 0.26)	0.31 (0.27 - 0.35)	1.05 (1.03 - 1.06)
Non-Hispanic/Latino	Reference	Reference	1.03 (1.03 - 1.03)
Hispanic/Latino	1.00 (0.997, 1.04)	1.00 (0.97 - 1.03)	1.03 (1.03 - 1.03)
Heart and Lung			
Non-Hispanic White	Reference	Reference	1.03 (1.03 - 1.03)
Black	0.38 (0.36 - 0.40)	0.68 (0.67 - 0.71)	1.06 (1.06 - 1.07)
Asian or Pacific Islander	0.60 (0.54 - 0.67)	0.79 (0.73 - 0.85)	1.4 (1.03 - 1.05)
American Indian or Alaska Native	0.22 (0.17 - 0.28)	0.27 (0.23 - 0.32)	1.04 (1.02 - 1.06)
Non-Hispanic/Latino	Reference	Reference	1.03 (1.03 - 1.03)
Hispanic/Latino	0.95 (0.91 - 1.00)	0.97 (0.93 - 1.00)	1.03 (1.03 - 1.04)
Abbreviation: aIRR, adjusted incidence rate ratio; CI, confidence interval.			

eTable 1. Crude Counts of Actual and Potential Donors per Year

Year	Number of Actual Donors	Number of Potential Donors
1999	5620	302340
2000	5756	298107
2001	5837	293136
2002	5911	289100
2003	6152	285560
2004	6811	271748
2005	7191	271765
2006	7623	267181
2007	7653	265255
2008	7619	267316
2009	7644	255462
2010	7624	258298
2011	7800	261004
2012	7797	259494
2013	7933	267699
2014	8266	274608
2015	8703	283521
2016	9632	294367
2017	9962	302239

eTable 2. Crude Counts of Actual and Potential Donors per Race per Year

Year	Race	Number of Actual Donors	Number of Potential Donors
1999	American Indian or Alaska Native	22	2433
	Asian or Pacific Islander	136	5576
	Black or African American	618	52090
	White	4262	221848
2000	American Indian or Alaska Native	15	2395
	Asian or Pacific Islander	136	5616
	Black or African American	660	51969
	White	4366	217251
2001	American Indian or Alaska Native	15	2384
	Asian or Pacific Islander	154	5902
	Black or African American	710	51666
	White	4311	211704
2002	American Indian or Alaska Native	21	2537
	Asian or Pacific Islander	132	5812
	Black or African American	750	50841
	White	4339	207793
2003	American Indian or Alaska Native	19	2709
	Asian or Pacific Islander	160	6107
	Black or African American	829	51828
	White	4374	202312
2004	American Indian or Alaska Native	24	2516
	Asian or Pacific Islander	166	5692
	Black or African American	953	49787

	White	4813	191965
2005	American Indian or Alaska Native	39	2713
	Asian or Pacific Islander	160	6152
	Black or African American	1093	49977
	White	4967	190208
2006	American Indian or Alaska Native	22	2640
	Asian or Pacific Islander	190	6200
	Black or African American	1193	49302
	White	5224	186182
2007	American Indian or Alaska Native	39	2699
	Asian or Pacific Islander	187	6196
	Black or African American	1205	49621
	White	5220	183503
2008	American Indian or Alaska Native	28	2771
	Asian or Pacific Islander	194	6363
	Black or African American	1234	48068
	White	5191	186000
2009	American Indian or Alaska Native	28	2868
	Asian or Pacific Islander	200	6435
	Black or African American	1246	44602
	White	5199	177573
2010	American Indian or Alaska Native	32	2799
	Asian or Pacific Islander	193	6423
	Black or African American	1283	46975
	White	5146	179024
2011	American Indian or Alaska Native	33	2951

	Asian or Pacific Islander	207	6435
	Black or African American	1245	46551
	White	5262	181450
2012	American Indian or Alaska Native	32	2918
	Asian or Pacific Islander	231	6651
	Black or African American	1329	46371
	White	5234	179618
2013	American Indian or Alaska Native	38	3059
	Asian or Pacific Islander	202	7137
	Black or African American	1335	48047
	White	5309	184650
2014	American Indian or Alaska Native	47	3300
	Asian or Pacific Islander	235	7255
	Black or African American	1298	48630
	White	5588	189511
2015	American Indian or Alaska Native	48	3431
	Asian or Pacific Islander	242	7660
	Black or African American	1423	50730
	White	5821	194494
2016	American Indian or Alaska Native	49	3445
	Asian or Pacific Islander	284	8158
	Black or African American	1513	53162
	White	6506	200551
2017	American Indian or Alaska Native	63	3606
	Asian or Pacific Islander	276	8577
	Black or African American	1550	54804
	White	6663	204873

eTable 3. Crude Counts of Actual and Potential Donors per Ethnicity per Year

Year	Ethnicity	Number of Actual Donors	Number of Potential Donors
1999	Hispanic or Latino	582	20393
	Not Hispanic or Latino or Not Stated	5038	281947
2000	Hispanic or Latino	579	20876
	Not Hispanic or Latino or Not Stated	5177	277231
2001	Hispanic or Latino	647	21480
	Not Hispanic or Latino or Not Stated	5190	271656
2002	Hispanic or Latino	669	22117
	Not Hispanic or Latino or Not Stated	5242	266983
2003	Hispanic or Latino	770	22604
	Not Hispanic or Latino or Not Stated	5382	262956
2004	Hispanic or Latino	855	21788
	Not Hispanic or Latino or Not Stated	5956	249960
2005	Hispanic or Latino	932	22715
	Not Hispanic or Latino or Not Stated	6259	249050
2006	Hispanic or Latino	994	22857
	Not Hispanic or Latino or Not Stated	6629	244324
2007	Hispanic or Latino	1002	23236
	Not Hispanic or Latino or Not Stated	6651	242019
2008	Hispanic or Latino	972	24114
	Not Hispanic or Latino or Not Stated	6647	243202
2009	Hispanic or Latino	971	23984

	Not Hispanic or Latino or Not Stated	6673	231478
2010	Hispanic or Latino	970	23077
	Not Hispanic or Latino or Not Stated	6654	235221
2011	Hispanic or Latino	1053	23617
	Not Hispanic or Latino or Not Stated	6747	237387
2012	Hispanic or Latino	971	23936
	Not Hispanic or Latino or Not Stated	6826	235558
2013	Hispanic or Latino	1049	24806
	Not Hispanic or Latino or Not Stated	6884	242893
2014	Hispanic or Latino	1098	25912
	Not Hispanic or Latino or Not Stated	7168	248696
2015	Hispanic or Latino	1169	27206
	Not Hispanic or Latino or Not Stated	7534	256315
2016	Hispanic or Latino	1280	29051
	Not Hispanic or Latino or Not Stated	8352	265316
2017	Hispanic or Latino	1410	30379
	Not Hispanic or Latino or Not Stated	8552	271860

eTable 4. Age and Sex-Standardized Incidence Rate Ratio of Donation in 2014 and 2017 for Potential Donors with Death due to HIV or Viral Hepatitis

	2014	2017	Yearly Increase
	aIRR (95% CI)	aIRR (95% CI)	aIRR (95% CI)
White	Reference	Reference	1.04 (1.02 – 1.05)
Black	0.61 (0.58 – 0.64)	0.46 (0.31 – 0.68)	1.02 (0.99 – 1.04)
Asian or Pacific Islander	0.87 (0.78 – 0.97)	0.70 (0.30 – 1.66)	1.02 (0.97 – 1.08)
American Indian or Alaska Native	0.27 (0.21 – 0.34)	0.56 (0.08 – 3.69)	1.08 (0.96 – 1.22)
Non-Hispanic/Latino	Reference	Reference	1.03 (1.02 – 1.04)
Hispanic/Latino	0.93 (0.89 – 0.98)	1.00 (0.66 – 1.51)	1.03 (1.01 – 1.06)

aIRR, adjusted incidence rate ratio; CI, confidence interval.

Chapter 3. Living Kidney Donor Socioeconomic Characteristics according to Race and Biologic Relationship to Recipient

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SIGNIFICANCE STATEMENT:

Historically, high end-stage renal disease risk among Black living kidney donors (LKD) who are biologically related to their recipient has been attributed to genetic risk. While socioeconomic status (SES) is a well-known explanatory contributor to racial disparities, multidimensional SES of LKDs is unmeasured at the population-level. Using a novel linkage between national, transplant registry and census-tract level American Community Survey data, we found that SES uniquely varied according to race and relationship among Black LKDs, with Black, related LKDs having lower SES than Black, unrelated LKDs and the lowest SES in the LKD population. While high ESRD risk for Black, related LKDs has historically been attributed to genetic risk, SES might be an explanatory contributor to this observed racial disparity.

ABSTRACT:

Background

Historically, high end-stage renal disease (ESRD) risk in Black living kidney donors (LKDs) who are biologically related to their recipient has been attributed to genetic risk. While socioeconomic status (SES) is linked to both race and relationship, it is unmeasured, incompletely conceptualized and insufficiently investigated at the population-level. Using a novel linkage between transplant registry and granular, census-tract level American Community Survey data, we examined the relationship between multidimensional SES, race and biologic relationship.

Methods

We computed a standardized SES measure using census-tract level measures (much more granular than ZIP code) that included household income, house value, households with nonwage income, education and occupation. We used linear regression to quantify the difference in SES according to race, adjusting for year, age, sex, and with an interaction term between race and biologic relationship to the recipient.

Results

Black LKDs possessed less income and wealth and were less educated and less often employed in high occupational classes than White LKDs; and these relationships persisted in summarized, adjusted SES measure. While there was no difference in SES according to relationship for the overall LKD population, there was an interaction between race and relationship for Black LKDs, with Black, related LKDs having a lower SES than Black, unrelated LKDs and the lowest SES of all race and relationship combinations in the LKD population.

Conclusions

While high ESRD risk for Black, related LKDs has historically been attributed to genetic risk, we found that SES uniquely varied according to biologic relationship for Black LKDs. Relatively lower SES of Black, related LKDs might be an explanatory contributor to observed racial disparities in ESRD risk.

INTRODUCTION

Historically, high end-stage renal disease (ESRD) risk among Black living kidney donors (LKDs) who are biologically related to their recipient has been attributed to genetic risk.¹⁰⁵⁻¹¹⁴ Socioeconomic status (SES), which denotes one's position within a social hierarchy and access to collective resources,^{17,115} is a well-known explanatory contributor to racial disparities in health outcomes.^{6,7} Furthermore, SES is shared among families and transmitted across generations.^{116,117} Given that socioeconomic status (SES) is linked to both race and relationship, it is possible that it contributes to observed ESRD risk variation according to race and biological relationship among LKDs. However, unmeasured socioeconomic data at the population-level has limited investigation of potential socioeconomic contributions to observed racial disparity in ESRD risk.

Prior studies have demonstrated that LKDs have higher incomes than the general, non-donor population and that living kidney donation rates are highest among the highest income groups.¹¹⁸ Race also modifies the relationship between income and donation rates with the Black population having lower donation rates than the White population at lower income groups, but higher donation rates in higher income groups.¹¹⁹ Income, however, is only one dimension of SES, and other dimensions, such as wealth and occupational class, have not been reported at the population-level. Furthermore, single dimension analyses fail to fully approximate the multidimensional, latent construct of SES.

Prior formative work on the socioeconomic characteristics of LKDs has also been limited by data availability. Specifically, prior income data for LKDs has been imputed using data aggregated from ZIP Codes, which were not created and intended for public health

research as they contain unpredictable geographic units with large populations of people that are socioeconomically heterogeneous. Alternatively, the US Census Bureau provides statistical units, such as census tracts, which are relatively small geographic units with an average population size of 4000 people that are socioeconomically homogenous.¹²⁰⁻

¹²³ For public health research, census-tract level socioeconomic data has been found to yield similar effect estimates as individual-level data,^{119,124-127} and are used by public health agencies to monitor social determinants of health. For LKDs, multidimensional SES using data intended for public health research has not been previously reported.

Therefore, the goal of this study was to use granular, census-based, population-level data to examine the relationship between multidimensional SES, race and biologic relationship to the recipient. We used a novel linkage between national, transplant registry and census-tract level American Community Survey data to (i) create a multidimensional SES measure and (ii) quantify differences in SES within the LKD population.

METHODS

Data sources

From the Scientific Registry of Transplant Recipients (SRTR), we obtained geocoded residential addresses of living kidney donors (LKDs) that were collected on the Organ Procurement Transplant Networks' Living Donor Registration Worksheet. The SRTR data system includes data on all donor, wait-listed candidates, and transplant recipients in the US, submitted by the members of the Organ Procurement and Transplantation Network (OPTN), and has been described elsewhere.⁵⁴ The Health Resources and

Services Administration (HRSA), U.S. Department of Health and Human Services provides oversight to the activities of the OPTN and SRTR contractors.

We linked SRTR data to the US Census Bureau's American Community Survey (ACS) using LKD Federal Inpatient Processing Standards state and county codes and census tract code. The ACS is a yearly national survey of over 3.5 million households that collects information on social, economic, housing and demographic characteristics of Americans and is used by federal, state, and local public officials and non-governmental planners to inform priorities for collective resources, such as housing, hospitals, schools, transportation, and emergency services. We used ACS data to impute socioeconomic indicators representing the multiple dimensions of socioeconomic status, a latent variable.¹²⁸ We used Social Explorer to obtain ACS 5-Year estimates, which are period estimates that are derived after collecting data over the course of the sample period rather than one point in time like the decennial census, for 2014-2018.

Study population

We identified all Black, Hispanic/Latino, and White LKDs who donated between 2015-2018 in the US for who residential address was complete for geocoding.

Socioeconomic Status Score

We examined each socioeconomic dimension individually and as a composite score. The ACS variables used were based on Diez Roux et al.'s factor analysis capturing several dimensions of SES (e.g. income, wealth, education, occupation) and included log median household income in the past 12 months by race of the householder

(B19001), log median house value for all owner-occupied housing units (B25077), percentage of households with interest, dividends, or net rental income (i.e. nonwage income) in the past 12 months (B19054), percent of census tract population that completed high school (B15003), percent of census tract population that completed college or more (B15003), percent of the civilian employed population 16 years and older that are employed in management, business, financial operations, and professional occupations (B17008) (Supplemental Table 1).¹²⁹ To create a composite score (i.e., SES score), we used Diez Roux et al.'s method of employing a Z-score transformation to put each socioeconomic dimension on the same scale for summing into an unweighted composite score.¹²⁹ We created Z-scores by subtracting the socioeconomic dimension's population mean across all LKD census-tracts from an individual LKD census-tract level value divided by the standard deviation of the dimension across all LKD census-tracts. We added all of the Z-scores together without any subjective weighting of individual socioeconomic dimensions according to relative importance. A SES of 0 is a SES equivalent to the living kidney donor population average. A negative SES represents a value below the population mean, while a positive score represents a value above the population mean. A one-unit change is equivalent to a standard deviation.

Differences Socioeconomic Dimensions and Score within Living Kidney Donor Population

We used linear regression to estimate the difference in standardized SES scores between racial groups, adjusting for age, sex, year, and biologic relationship to the recipient. We performed a Wald test to test whether the mean SES was the same across racial groups. To determine whether racial differences in SES differed according to

biologic relationship to the recipient, we incorporated an interaction variable between race and biological relationship to the recipient into multiple linear regression model.

Statistical analysis

All analyses were performed using Stata 16.1/MP for Linux (College Station, Texas).

RESULTS

Study Population

We studied 20,084 Black, Hispanic/Latino, and White living kidney donors across 16,812 unique census tracts. We removed 654 (3%) LKDs because missing ACS data precluded computation of SES score.

Differences in the Dimensions of Socioeconomic Status

For the socioeconomic dimension of income, Black and Hispanic LKDs had lower incomes than White LKDs (Median household income (95% CI) for White = \$72,907 (\$56,088, \$96,638), Black = \$51,397 (\$34,791, \$72,500), Hispanic/Latino = \$54,035 (\$40,988, \$73,527), $p < 0.001$) (Table 1, Figure 1). For the socioeconomic dimension of wealth, Black and Hispanic LKDs had less wealth than White LKDs as measured by house value and houses with non-wage income (i.e., interest, dividends, rental income) (Median house value (95% CI) for White = \$226,200 (\$154,500, \$355,600), Black = \$179,800 (\$120,800, \$285,700.), Hispanic/Latino = \$224,500 (\$137,500, \$370,700), $p < 0.001$; Percent of houses with non-wage income (95% CI) for White = 24% (17%, 32%), Black = 13% (8%, 20%), Hispanic/Latino = 14% (8%, 21%), $p < 0.001$) (Figure 2-3). For the socioeconomic dimension of education, Black and Hispanic LKDs were less

educated than White LKDs (Percent high school educated (95% CI) for White = 23% (16%, 31%), Black 26% (20%, 32%) and Hispanic = 25% (20%, 31%), $p < 0.001$ (Figure 4); Percent more than college educated for White = 34% (22%, 50%), Black = 26% (16%, 38%), and Hispanic = 22% (13%, 35%), $p < 0.001$) (Figure 5). For the socioeconomic dimension of occupation, Black and Hispanic LKDs were less often employed in high occupational classes than White LKDs (Percent employed in executive, managerial, or professional occupations for White = 41% (32%, 52%), Black = 34% (25%, 44%), and Hispanic/Latino = 30% (20%, 41%), $p < 0.001$) (Figure 6).

For the socioeconomic dimension of income, related LKDs had lower incomes than unrelated LKDs (Median household income (95% CI) for related = \$65,972 (\$49,545, \$89,250), unrelated = \$70,426 (\$53,361, \$94,076), $p < 0.001$) (Table 2). For the socioeconomic dimension of wealth, related LKDs had less wealth than related LKDs as measured by house value and houses with non-wage income (i.e., interest, dividends, rental income) (Median house value (95% CI) for related = \$218,100 (\$145,400, \$349,300), unrelated = \$225,100 (\$152,700, \$354,500), $p < 0.001$); Percent of houses with non-wage income (95% CI) for related = 21% (14%, 29%), unrelated = 23% (16%, 31%), $p < 0.001$). For the socioeconomic dimension of education, related LKDs were less educated than unrelated LKDs (Percent high school educated (95% CI) for related = 25% (18%, 31%), unrelated = 24% (16%, 31%), $p < 0.001$; Percent more than college educated for related = 30% (19%, 46%), unrelated = 33% (21%, 48%), $p < 0.001$). For the socioeconomic dimension of occupation, related LKDs were less often employed in a high occupation classes than unrelated LKDs (Percent employed in executive, managerial, or professional occupations for related = 38% (28%, 49%), unrelated = 40% (31%, 51%), $p < 0.001$).

Differences in Composite Socioeconomic Status Measure

When the socioeconomic dimensions were standardized to the LKD population mean and combined into a score, Black and Hispanic LKDs had lower SES than White LKDs (Median [IQR] SES score for White = 0.70 (-1.46, 3.16), Black = -2.08 (-4.31, 0.37), and Hispanic/Latino = -2.01 (-4.37, 0.39), $p < 0.001$) (Figure 2). After adjusting for age, sex, year, and biologic relationship to the recipient, Black and Hispanic LKDs had a SES 2.56 and 2.45 less than White LKDs (Table 4) and was significantly different across racial groups ($p < 0.001$).

While SES dimensions varied according to biologic relationship to the recipient, when dimensions were summarized in a standardized SES score and adjusted for race, age, sex, and donation year, there was no difference in SES according to biologic relationship to the recipient (SD for related versus unrelated = -0.01, 95% CI: -0.10, 0.10) (Table 3). However, there was an interaction between race and biologic relationship to the recipient among Black donors, with Black, related LKDs having the lower SES than Black, unrelated LKDs (P value for interaction = 0.001, SD for Black, related LKDs versus Black, unrelated LKDs = -0.49, 95% CI = -0.80, -0.18). Black LKDs who were biologically related to their recipient also had the lowest SES of all race and relationship combinations in the LKD population (Figure 7).

DISCUSSION

In this population-based study of LKDs using a novel linkage between national, transplant registry and census-tract level American Community Survey data, we found

that Black and Hispanic and related LKDs possess less income and wealth, are less educated, and are less often employed in executive, managerial, or professional occupations than White and unrelated LKDs. When individual SES dimensions were summarized in a SES measure, there was no difference in SES according to biologic relationship to the recipient, but racial differences in SES remained. SES differences were particularly salient at the intersection of race and biological relationship to the recipient among Black LKDs, with Black, related LKDs having lower SES than Black, unrelated LKDs and the lowest SES of all race and relationship combinations in the LKD population. In contrast, a difference in SES according to biological relationship to the recipient was not observed among White and Hispanic LKDs.

Our finding that LKDs who are not biologically related to their recipient are more highly educated, and possessed more income and wealth than LKDs who are related to their recipient is consistent with prior research.¹²⁵ Our results are inconsistent, however, with Gore et al who used ZIP code data to create a SES measure using the same methodology as our present study and found LKDs who were not biologically related to their recipient were higher SES.¹²⁵ Our results are likely different than this study because we have used more granular census-tract level data and multivariable regression to adjust for factors that are known to be related to SES (i.e., race, age, sex, and time) and isolate the relationship between biologic relationship to the recipient and SES. Given our data and methods, our results are likely a better estimate of the difference according to biologic relationship to the recipient. Our finding that SES uniquely varies according to biologic relationship to the recipient among Black LKDs might not be unexpected given that it is known that LKDs who are not related to their recipient are more often White and

more highly educated than LKDs who are related to their recipient, and most Black LKDs are related, first-degree relatives, to their recipient.

In the absence of data on the SES of LKDs at the population level, observed racial variation in post-donation ESRD at the intersection of Black race and biologic relationship to the recipient using observational, transplant registry data has been attributed to genetic differences,¹¹⁴ and influenced clinical practice. Over time, the greatest declines in living kidney donation rates have been observed among Black LKDs who are related to their recipient,¹³⁰ and Black LKDs now experience a unique donor evaluation process with some transplant centers routinely screening for Apolipoprotein L1 (APOL1) and considering high-risk genotypes strict contraindications to donation.^{131,132} From general chronic kidney disease (CKD) population research, it is known that SES is associated with and partially explains racial disparities in kidney function decline and incident ESRD.¹³³⁻¹⁴¹ SES also influences the relationship between APOL1 and kidney function decline.¹⁴²⁻¹⁴⁴ Our work is important because we have performed the first step necessary to investigate whether SES is associated with ESRD risk variation among LKDs, mediates or moderates the relationship between race and post-donation ESRD risk, and/or interacts with known genetic risk factors.

Our work is not without limitations. SES measurement is inherently challenging given its latent nature. First, to create our SES measurement, we used a previously published methodology based using factor analysis of 1990 Census data. Though the measurements are exactly the same in our study, it is possible that the relationship between incorporated SES dimensions could have changed over time. Additionally, we

used a linear combination of dimensions to create our SES score instead of applying weights to individual dimensions, which might mean that our SES score is not an accurate representation of latent SES. However, the alternative of arbitrarily weighting individual dimensions of a latent construct is also error prone. Lastly, we treated census-tract level measurements of socioeconomic dimensions as surrogates for individual-level data (i.e., measurements are not patient-reported), which could theoretically misclassify individuals. However, comparisons of socioeconomic inequalities in health using individual-level data to census-tract level data have been found to yield similar results,¹⁴⁵ and many dimensions are unmeasured in registry data.

In this study, leveraging a novel linkage between national, transplant registry data and census-tract level American Community Survey data, we found that SES differs according to biologic relationship among Black LKDs, with Black, related LKDs having lower SES. While ESRD risk differences according to Black race and biologic relationship have historically been attributed to genetic risk, SES might be an explanatory contributor.

Table 1. Socioeconomic Characteristics of Living Kidney Donors according to Race

	White	Black	Hispanic/Latino	p-value
	N=15508	N=1783	N=2793	
Age, Median [IQR]	46 (36, 54)	38 (30, 48)	38 (30, 47)	<0.001
Female Sex, N (%)	9856 (63.6%)	1097 (61.5%)	1794 (64.2%)	0.16
Biologically related to recipient, N (%)	6089 (39.3%)	1068 (59.9%)	1618 (57.9%)	<0.001
Median Household Income, Median [IQR]	72,907 (56,088, 96,638)	51,397 (34,791, 72,500)	54,035 (40,988, 73,527)	<0.001
Median House Value, Median [IQR]	226,200 (154,500, 355,600)	179,800 (120,800, 285,700)	224,500 (137,500, 370,700)	<0.001
% Household's w/interest, Median [IQR]	24% (17%, 32%)	13% (8%, 20%)	14% (8%, 21%)	<0.001
% HS, Median [IQR]	23% (16%, 31%)	26% (20%, 32%)	25% (20%, 31%)	<0.001
% More than College Educated	34% (22%, 50%)	26% (16%, 38%)	22% (13%, 35%)	<0.001
% Employed in executive, managerial, or professional occupations	41% (32%, 52%)	33% (25%, 44%)	30% (20%, 41%)	<0.001
Socioeconomic Status score, Median [IQR]	0.70 (-1.46, 3.16)	-2.08 (-4.31, 0.38)	-2.01 (-4.27, 0.40)	<0.001

Table 2. Socioeconomic Characteristics of Living Kidney Donors according to Biologic Relationship to the Recipient

	Related	Unrelated	P value
	N=8775	N=11309	
Age, median [IQR]	41 (31, 51)	46 (36, 54)	<0.001
Sex, N (%)	5340 (61%)	7407 (65.5%)	<0.001
Race, N (%)			<0.001
White	6089 (69.4%)	9419 (83.3%)	
Black	1068 (12.2%)	715 (6.3%)	
Hispanic	1618 (18.4%)	1175 (10.4%)	
Median Household Income	65,972 (49,545, 89,250)	70,426 (53,361, 94,076)	<0.001
Median House Value	218,100 (145,400, 349,300)	225,100 (152,700, 354,500)	<0.001
% Household's w/interest	21% (14%, 29%)	23% (16%, 31%)	<0.001
% High School Educated	25% (18%, 31%)	24% (16%, 31%)	<0.001
% More than College Educated	30% (19%, 46%)	33% (21%, 48%)	<0.001
% Employed in executive, managerial, or professional occupations	38% (28%, 49%)	40% (31%, 51%)	<0.001
Socioeconomic Status score, Median [IQR]	-0.17 (-2.48, 2.40)	0.35 (-1.11, 2.82)	<0.001

Figure 1. Violin Plot Comparison of Median Household Income according to Race

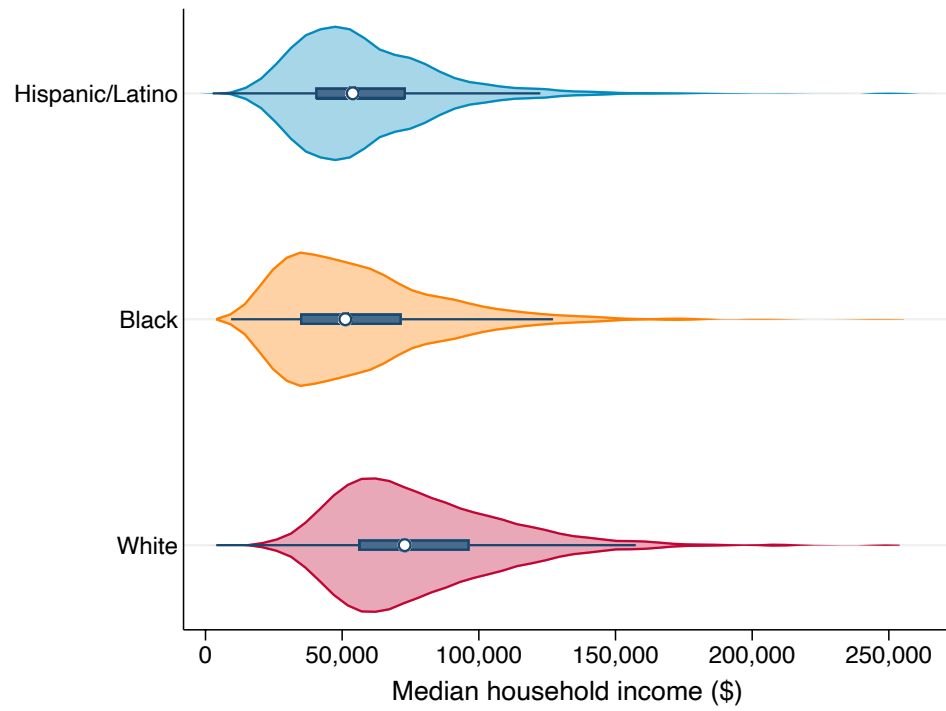


Figure 2. Violin Plot Comparison of Median House Value according to Race

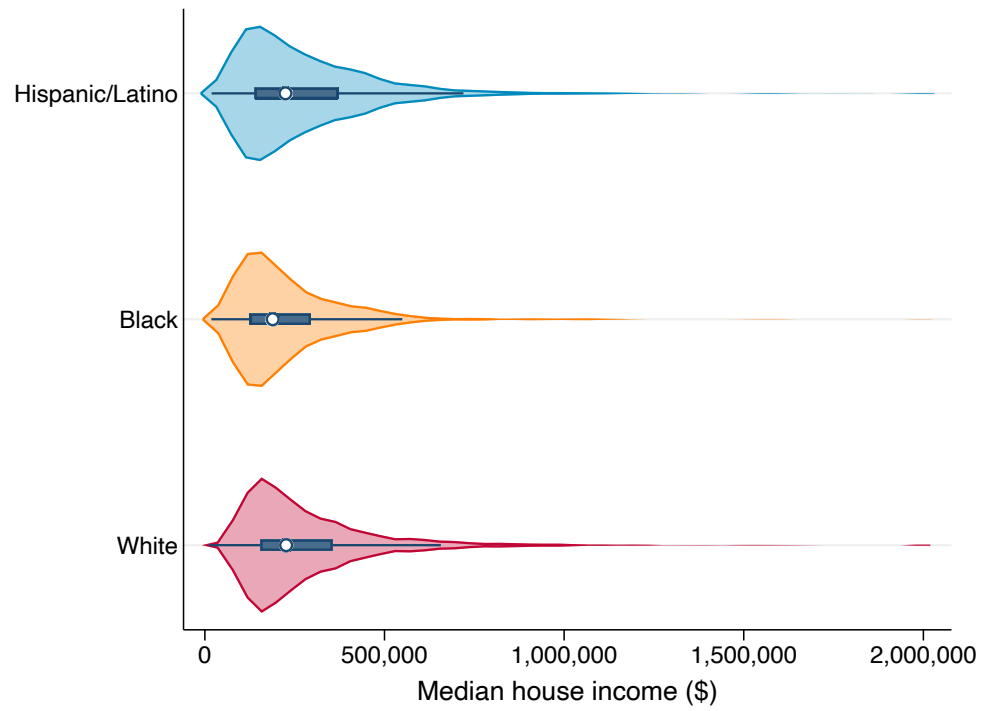


Figure 3. Violin Plot Comparison of Households with non-Wage Income according to Race

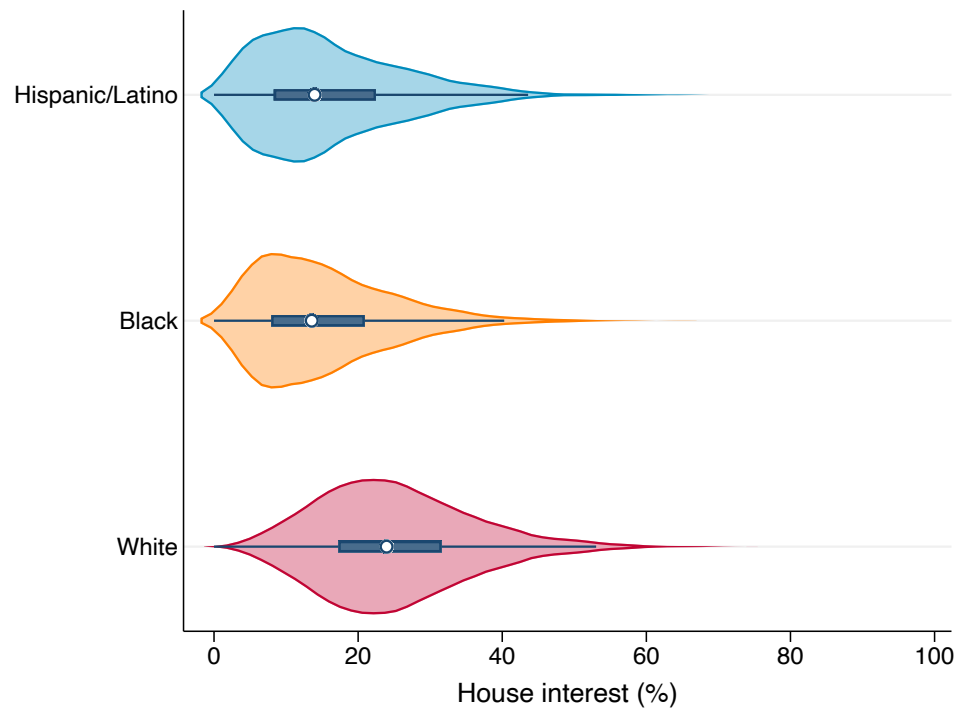


Figure 4. Violin Plot Comparison of Percent High School Educated according to Race

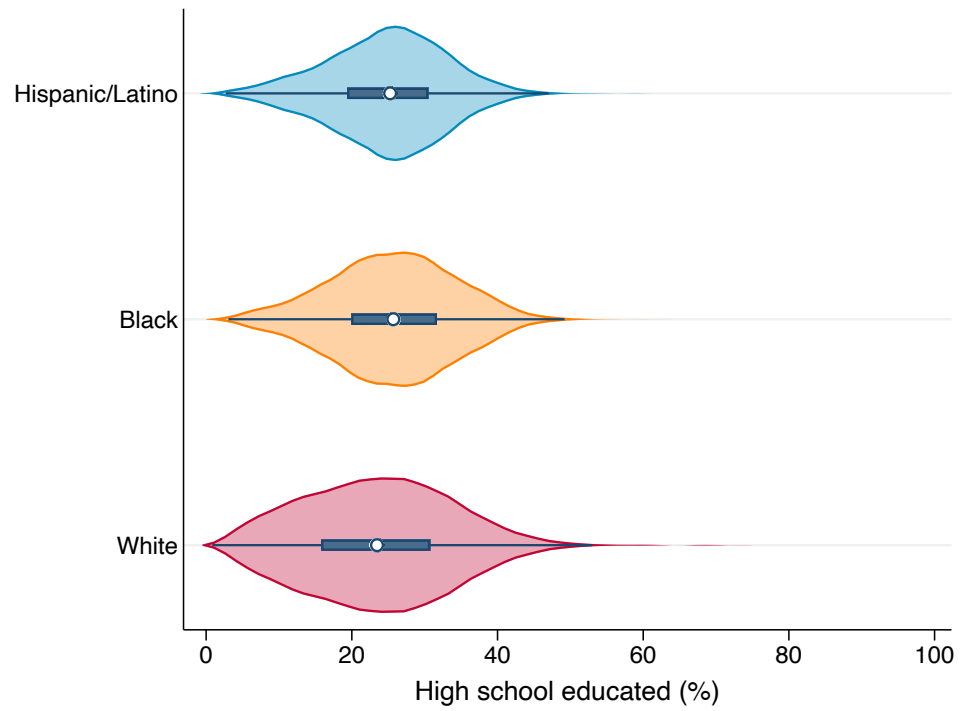


Figure 5. Violin Plot Comparison of College Educated or More according to Race

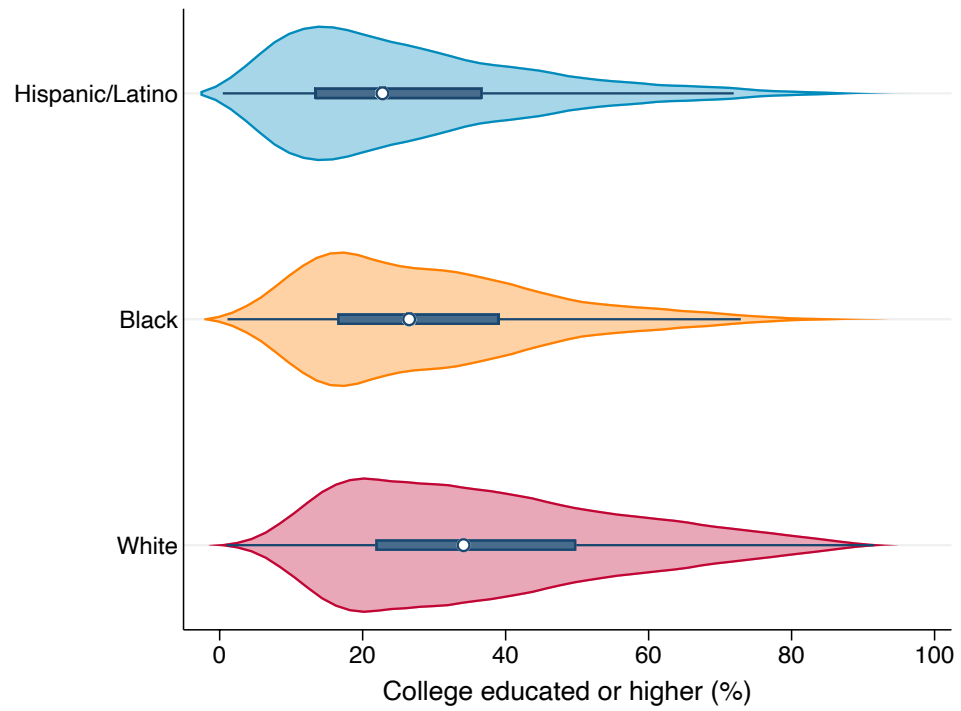


Figure 6. Violin Plot Comparison of Percent High Occupational Class Income according to Race

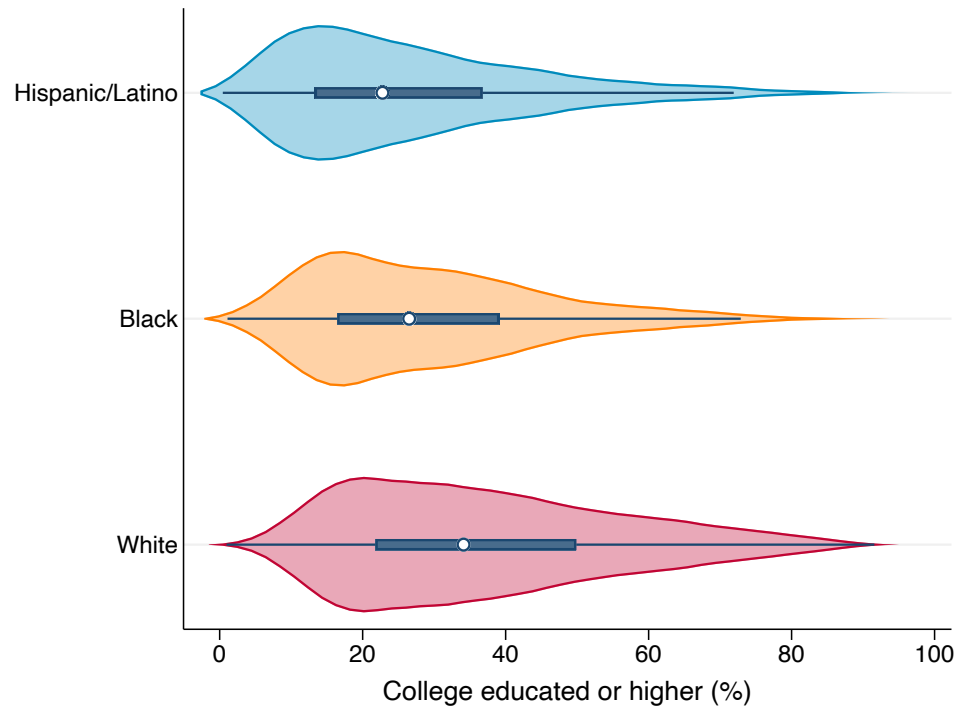
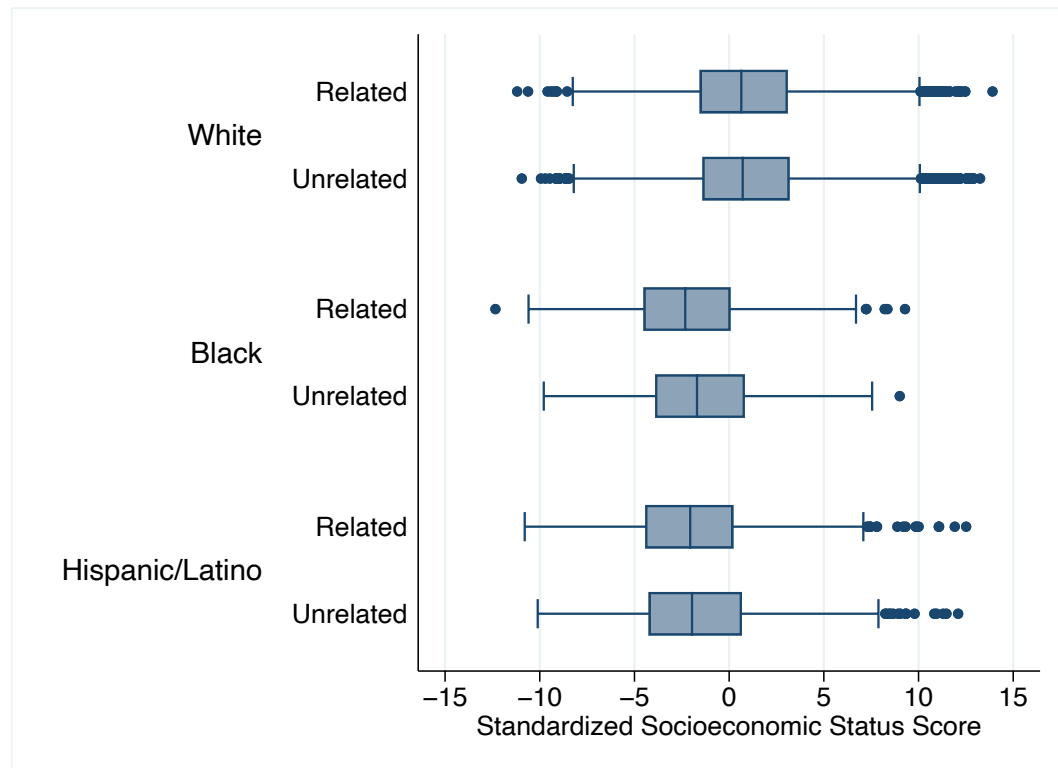


Figure 7: Distribution of Standardized Socioeconomic Status according to Race and Biologic Relationship to Recipient



A socioeconomic status score (SES) of 0 is a SES equivalent to the living kidney donor population average. A negative SES represents a value below the population mean, while a positive score represents a value above the population mean. A one-unit change is equivalent to a standard deviation.

Table 3. Differences in Standardized Socioeconomic Status

Covariate	Unadjusted Socioeconomic Score Difference (95% CI)	Adjusted Socioeconomic Score Difference (95% CI)
Race		
White	Reference	Reference
Black	-2.85 (-3.02, -2.68)	-2.56 (-2.73, -2.39)
Hispanic	-2.73 (-2.88, -2.60)	-2.45 (-2.59, -2.31)
Age	0.06 (0.06, 0.07)	0.04 (0.4, 0.05)
Sex		
Male	Reference	Reference
Female	-0.09 (-0.19, 0.02)	-0.16 (-0.26, -0.06)
Year	0.14 (0.11, 0.18)	0.11 (0.08, 0.14)
Relationship		
Unrelated	Reference	Reference
Related	-0.54 (-0.64, -0.44)	-0.01 (-0.10, 0.10)

Supplemental Table 1: Variables for SES Score

Variable Name	Socioeconomic Dimension	American Community Survey Table
Median Household Income	Income	b19013001
Median House Value	Wealth	b25071001
% Households with non-Wage Income	Wealth	b19054002)/b19054001
% High School Educated	Education	(b15003016 + b15003017)/b15003001
% College Educated	Education	(b15003022 + b15003023 + b15003024 + b15003025)/b15003001
% Employed in executive, managerial, or professional occupations	Occupation	(b17008_002* + b17008_003*)/b17008_001*

*Social Explorer Table

Chapter 4. Medicaid Expansion Provision of Patient Protection and Affordable Care Act's Effect on Kidney Transplant Waitlist Registrations

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authors alone and do not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products or organizations imply endorsement by the U.S. Government. The data reported here have been supplied by the Hennepin County Research Institute (HHRI) as the contractor for the Scientific Registry of Transplant Recipients (SRTR). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy of or interpretation by the SRTR or the U.S. Government.

MINI-ABSTRACT:

Insurance status and payer type are determinants of kidney transplant waitlisting. This study examines how the Affordable Care Act's Medicaid expansion provision affected waitlisting. While Medicaid expansion was associated with increased waitlist registrations, increases were differential across sociodemographic groups with minority and low-income adults having smaller increases.

ABSTRACT:

Objective:

To examine how Medicaid expansion affected kidney transplant waitlisting for different sociodemographic groups.

Summary of Background Data:

Insurance status and payer type are kidney transplant access determinants and contribute to disparities. In 2014, the Patient Protection and Affordable Care Act's Medicaid expansion provision extended health insurance to more low-income adults. The effect of this policy on waitlisting has not been evaluated.

Methods:

We performed an observational cohort study of adults with end-stage renal disease using Scientific Registry of Transplant Recipients data from 2012-2018. We used Poisson regression and generalized estimating equations to estimate change in waitlist registrations in expansion and non-expansion states.

Results:

In Medicaid expansion states, there was a 57% increase in Medicaid-insured waitlist registrants (incidence rate ratio [IRR]: 1.57, 95% CI: 1.50-1.65). Waitlist registrant increases were greatest among White and Hispanic/Latino populations, and the least among Black and Asian populations (IRR for White individuals: 1.55, 95%CI: 1.42-1.69, IRR for Hispanic/Latino individuals: 1.31, 95%CI: 1.27-1.35, IRR for Black individuals: 1.26, 95%CI: 1.19-1.33, and IRR for Asian individuals: 1.10, 95%CI: 1.03-1.17). There was a graded effect according to income, with relatively higher income quartiles having

the greatest registrant increases (IRR for incomes \$7,333-41,906: 1.05, 95%CI: 0.99-1.12, IRR for incomes \$41,912-54,308: 1.17, 95%CI: 1.10-1.24, IRR for incomes \$54,309-72,218: 1.52, 95%CI: 1.43-1.63, IRR for incomes \$72,227-250,001: 1.92, 95%CI: 1.75-2.12). There was no differential age benefit.

Conclusions and Relevance:

While Medicaid expansion increased kidney transplant waitlist registrations, increases were differential across sociodemographic groups with racial minority and low-income adults having smaller increases.

INTRODUCTION

In the United States, insurance status and payer type are important determinants of access to kidney transplantation.¹⁴⁶ Patients with end-stage renal disease (ESRD) who additionally qualify for Medicaid because of financial need, or who are uninsured, are less likely to be evaluated,^{147,148} listed,^{149,150} and transplanted as compared to privately insured patients.¹⁵¹ Access disparities according to insurance payer type are particularly pronounced among young patients,¹⁵⁰ leaving young, low-income patients with decreased access to kidney transplant and its benefits of survival and increased quality of life.¹⁵²

The Patient Protection and Affordable Care Act (ACA) initially required that states expand their Medicaid eligibility requirements to include more low-income, non-disabled adults without children effective 2014. However, following a Florida initiated lawsuit and subsequent case known as *National Federation of Independent Business v. Sebelius, Secretary of Health and Human Services*,¹⁵³ the Supreme Court found Medicaid expansion unconstitutionally coercive to states and it became optional.¹⁵⁴

Notwithstanding, the ACA's aim was partially achieved and there was a 9.3% decline in uninsured rates in Medicaid expansion states as compared to only a 3.7% decline in non-Medicaid expansion states, with the greatest healthcare coverage gains appreciated for most racial/ethnic minority groups in Medicaid expansion states.¹⁵⁵ Additionally, Medicaid expansion was associated with increased patient-reported ease of access to a personal physician and medications,¹⁵⁶ healthcare utilization,^{157,158} quality of care,¹⁵⁹ preventative care, affordability, and diagnosis and treatment of chronic conditions.¹⁶⁰⁻¹⁶²

For patients with ESRD, Medicaid expansion was associated with a 10.5% increase in having Medicaid insurance at dialysis initiation and a 2.3% increase in permanent hemodialysis access.¹⁶³ While pre-emptive listings for living kidney transplant increased following Medicaid expansion,^{164,165} it is not known how Medicaid expansion affected access to deceased donor kidney transplantation for the intended sociodemographic group targets of financial needs-based insurance.

The goal of this study was to characterize national trends in incident kidney transplant waitlist registrations in states that adopted Medicaid expansion versus those that did not. Therefore, we used transplant registry and Census data to quantify incident waitlist registrations according to insurance payer type within strata of age, race, and income.

METHODS

Data sources

This study used data from the Scientific Registry of Transplant Recipients (SRTR) and the US Census Bureau's American Community Survey (ACS). The SRTR data system includes data on all donor, wait-listed candidates, and transplant recipients in the US, submitted by the members of the Organ Procurement and Transplantation Network (OPTN). The Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services provides oversight to the activities of the OPTN and SRTR contractors. Details of these data has been described elsewhere.⁵⁴ The ACS is a national, yearly, household survey that collects information on social, economic, housing, and demographic characteristics from US residents.

Study population

We identified all adult (≥ 18 years) US-resident incident deceased donor kidney transplant registrants from January 1, 2012 to December 31, 2018.

States adopting Medicaid Expansion

We used Kaiser Family Foundation reporting to determine which states (including DC) adopted Medicaid expansion by the end of 2018.¹⁶⁶ Given that the timing of Medicaid expansion was not uniform across states, we then divided our study population into 2 groups according to the date of Medicaid expansion: (i) January 1, 2014 (n=25 states), and (ii) April 1, 2014 to July 1, 2016 (n=7 states).

National-level trends in waitlist registrations

We used Poisson regression to examine how national trends in insurance varied over time in states that adopted Medicaid expansion on January 1, 2014 and non-Medicaid expansion states. We categorized registrants according to their primary insurance type at listing, which included private, Medicaid, Medicare, and other public insurance (i.e., Department of Veterans Affairs or other government sponsored insurance). For patients with Medicare, we only included registrants less than 65 years old.

State-level trends in waitlist registrations

We used generalized estimating equations with a Poisson distribution to evaluate the state-level trends in the number of incident waitlist registrations per workday each month (>98% of incident listings occurred on workdays) according to primary insurance at listing. Analyses were further stratified by race/ethnicity, age, and median household income. We used 2014-2018 ACS 5-year estimates of median household income according to registrant 5-digit ZIP Code Tabulation Area (ZCTA) corresponding to registrant ZIP codes available to August 31, 2017. We excluded registrants for who there

was no ZIP code (n=227 from 32 states, 0.1%) or ZCTA for their ZIP code (n=2305 from 51 states, 1.2%). Additionally, we excluded registrants that did not have a median household income estimate, due to data suppression,¹⁶⁷ from the income sub-analysis (n=218 from 46 states, 0.1%).

Statistical analysis

All analyses were performed using Stata 16.0/MP for Linux (College Station, Texas).

RESULTS

Study population

We identified 248,905 US-resident kidney registrants waitlisted for kidney transplant; 155,754 (62.6%) resided in states that adopted Medicaid expansion. Of these 155,754 registrants, 127,255 (48.1%) resided in states that adopted Medicaid expansion on January 1, 2014, and 28,499 resided in states that adopted Medicaid expansion between April 1, 2014 and January 1, 2016 (Table 1).

Medicaid expansion states were more likely to have registrants who had Medicaid (Medicaid expansion January 2014: 51.2%, Medicaid expansion April 2014-July 2016: 53.2% vs. non-Medicaid expansion: 47.2%) or Private insurance (Medicaid expansion January 2014: 12.9%, Medicaid expansion April 2014-July 2016: 9.3% vs. non-Medicaid expansion: 4.6%, $p<0.001$) at the time of listing than non-Medicaid expansion states. Medicaid expansion states were more likely to have registrants aged 50-64 years (Medicaid expansion January 2014: 43.8%, Medicaid expansion April 2014-July 2016: 43.3% vs. non-Medicaid expansion: 42.4%, $p<0.001$). Moreover, Medicaid expansion states were less likely to have Black registrants (Medicaid expansion January 2014:

23.1%, Medicaid expansion April 2014-July 2016: 31.7% vs. non-Medicaid expansion: 36.3%, $p<0.001$), and more likely to have Hispanic/Latino registrants (Medicaid expansion January 2014: 21.2%, Medicaid expansion April 2014-July 2016: 4.4% vs. non-Medicaid expansion: 16.6%, $p<0.001$).

National-level trends in waitlist registrations

In states that adopted Medicaid expansion on January 1, 2014, there was a 57% increase in the number of Medicaid-insured incident registrants (incidence rate ratio [IRR]: 1.57, 95% CI: 1.50-1.65, $p<0.001$) (Figure 1A). There was a 16% decrease in Medicare-insured registrants <65 years old (IRR: 0.84, 95% CI: 0.81-0.86, $p<0.001$). There were no significant changes among privately insured registrants. In non-Medicaid expansion states, there were no statistically significant changes in incident waitlist registrants with Medicaid or Medicare insurance (Figure 1B). However, there was a 16% increase in privately insured registrants (IRR: 1.16, 95% CI: 1.13-1.20, $p<0.001$).

State-level trends in waitlist registrations

Trends according to race

The effects of Medicaid expansion varied according to race. In Medicaid expansion states, there was a 55%, 31%, 26% and 10% increase in the number of incident Medicaid-insured registrants among Whites, Hispanic/Latinos, Blacks, and Asians, respectively (IRR for Whites: 1.55, 95%CI: 1.42-1.69, IRR for Hispanic/Latinos: 1.31, 95%CI: 1.27-1.35, IRR for Blacks: 1.26, 95%CI: 1.19-1.33, and IRR for Asians: 1.10, 95%CI: 1.03-1.17) (Table 2). There was less variation in privately and Medicare-insured waitlist registrations according to race. Among the privately insured living in Medicaid expansion states, waitlist registrations decreased across all racial groups (IRR for Whites: 0.95, 95%CI: 0.94-0.96, IRR for Hispanic/Latinos: 0.86, 95%CI: 0.84-0.87, IRR

for Blacks: 0.88, 95% CI: 0.86-0.90, and IRR for Asians: 0.82, 95%CI: 0.79-0.84).

Among the Medicare-insured, waitlist registrations also decreased across all racial groups (IRR for Whites: 0.89, 95%CI: 0.87-0.91, IRR for Hispanic/Latinos: 0.86, 95%CI: 0.84-0.87, IRR for Blacks: 0.78, 95% CI: 0.76-0.79, and IRR for Asians: 0.90, 95%CI: 0.86-0.94).

Trends according to income

The Medicaid expansion effect varied according to median household income, with higher incomes being associated with an increase in waitlist registrations. There was no increase in Medicaid-insured incident waitlist registrations for the lowest income quartile (IRR for incomes \$7,333-41,906: 1.05, 95%CI: 0.99-1.12). For the other income quartiles, waitlist registrations increased by 17%, 52%, and 92% (IRR for incomes \$41,912-54,308: 1.17, 95%CI: 1.10-1.24, IRR for incomes \$54,309-72,218: 1.52, 95%CI: 1.43-1.63, IRR for incomes \$72,227-250,001: 1.92, 95%CI: 1.75-2.12) (Table 3). In Medicaid expansion states, there were decreases in waitlist registrations among those with private insurance across all income quartiles with the exception of the highest income quartile (IRR for incomes \$7,333-41,906: 0.77, 95%CI: 0.75-0.80, IRR for incomes \$41,912-54,308: 0.77, 95%CI: 0.75-0.79, IRR for incomes \$54,309-72,218: 0.87, 95%CI: 0.85-0.88, IRR for incomes \$72,227-250,001: 1.07, 95%CI: 1.06-1.08). Trends in Medicare-insured registrations were similar to private insurance trends (IRR for incomes \$7,333-41,906: 0.82, 95%CI: 0.79-0.85, IRR for incomes \$41,912-54,308: 0.76, 95%CI: 0.74-0.78, IRR for incomes \$54,309-72,218: 0.88, 95%CI: 0.86-0.91, IRR for incomes \$72,227-250,001: 1.11, 95%CI: 1.08-1.14).

Trends according to age

Primary insurance type of waitlist registrants did not vary significantly across age strata. In Medicaid expansion states, Medicaid-insured waitlist registrations increased similarly across all age groups with the exception of those greater than 65 years old (IRR for 18-26 years: 1.41, 95%CI: 1.24-1.60, IRR for 27-39 years: 1.38, 95%CI: 1.30-1.47, IRR for 40-49 years: 1.24, 95%CI: 1.17-1.32, IRR for 50-64 years: 1.41, 95%CI: 1.35-1.47, IRR for ≥ 65 years: 1.04, 95%CI: 0.90-1.21) (Table 4). Waitlist registrations among those with private insurance decreased similarly across age groups (IRR for 18-26 years: 0.92, 95%CI: 0.87-0.99, IRR for 27-39 years: 0.96, 95%CI: 0.94-0.98, IRR for 40-49 years: 0.90, 95%CI: 0.88-0.92, IRR for 50-64 years: 0.91, 95%CI: 0.90-0.92, IRR for ≥ 65 years: 0.91, 95%CI: 0.90-0.92). Similar to private insurance trends, the number of Medicare-insured registrants also decreased (IRR for 18-26 years: 0.79, 95%CI: 0.71-0.87, IRR for 27-39 years: 0.92, 95%CI: 0.89-0.95, IRR for 40-49 years: 0.81, 95%CI: 0.79-0.83, IRR for 50-64 years: 0.83, 95%CI: 0.82-0.84).

DISCUSSION

In this national study of kidney transplant waitlisting following Medicaid expansion, we found that there was a 57% increase in Medicaid-insured incident waitlist registrants in Medicaid expansion states. While there was a 10-55% increase in waitlist registrations across all racial groups, the greatest increases were seen among White and Hispanic/Latino registrants, and the least among Black and Asian registrants. For Medicaid-insured waitlist registrants, there was a graded relationship between income and waitlisting, with the greatest increases in waitlist registrations being observed among the highest income quartiles.

Our findings of an overall increase in number of waitlist registrants in Medicaid expansion states is consistent with what has been observed among lung,¹⁶⁸ liver,¹⁶⁹ and heart transplant listings.¹⁷⁰ In a randomized controlled trial of Medicaid coverage in one state, extending Medicaid to low-income adults was associated with an increase in outpatient and preventative care, prescription drug use for chronic morbidities,¹⁷¹ and financial well-being,¹⁷²⁻¹⁷⁴ and decrease in health insurance disruptions.^{175,176} Observational studies have demonstrated that Medicaid expansion was associated with increases in presentation of early, uncomplicated surgical disease,^{177,178} and outpatient surgery.¹⁷⁹ For patients with ESRD, Medicaid expansion was associated with an increase in arteriovenous access use at dialysis initiation,¹⁶³ providing evidence of increased healthcare utilization and timely healthcare. Therefore, it might be that our observed increase in waitlist registrations in Medicaid expansion states was due to more frequent outpatient care and better control of chronic health conditions.

We found that of all racial minority groups, Black and Asian registrants had the smallest increases in waitlist registrations in Medicaid expansion states, which is not unexpected given that racial disparities are known to exist at referral, evaluation and waitlisting.^{180,181} Black patients with ESRD less often start and complete transplant evaluation, and have longer completion times for each step as compared to White patients.¹⁸² Socioeconomic differences between racial groups do not fully explain racial disparities in waitlisting.^{182,183} In a survey of adult ESRD patients referred for transplant evaluation at three transplant centers in the Southeast, high medical mistrust and perceived racism, and experiences with discrimination were associated with not initiating transplant evaluation and were more often experienced by Black patients than non-Black patients.¹⁸⁴ Transplant provider beliefs and perceptions of candidate psychosocial factors also affect waitlisting

decisions. Of Black patients initiating dialysis, patients who were not counseled about transplantation were 27% more likely than those receiving counsel to have psychosocial factors unsuitable for transplant.¹⁴⁸ In a discrete choice experiment used to elicit preferences, perception of adequate social support was highly important to providers concerned with organ waste, but less important to providers concerned with fairness of subjective social support criterion.¹⁸⁵ Our findings suggest that addressing socioeconomic indicators alone is not sufficient to eliminate relatively lower waitlisting rates among some racial minorities. In contrast to the Black population, we found that the Hispanic/Latino population was the minority group that benefit the most from Medicaid expansion, which is consistent with general population research highlighting greater decreases in uninsurance rates among Hispanics than Blacks when compared to Whites.^{155,186}

While an aim of Medicaid expansion was to address the historical “coverage gap” of low-income adults, we found that there was a graded increase in kidney transplant waitlist registrations according to income, with the exception of the poorest waitlisted candidates. Prior studies have demonstrated that income is a socioeconomic indicator that is independently associated with waitlisting. In a content analysis of ethics consultations at a single institution, almost one-third of the consultations were related to financial and/or insurance barriers to transplantation.¹⁴⁶ There is also a significant interaction between income and race. Dialysis facilities serving patients in high poverty neighborhoods have the lowest transplant referral rates,¹⁸⁷ and neighborhood poverty differentially affects Black versus White patients, with Black patients in the poorest neighborhoods being 57% less likely than White patients to be listed.^{188,189}

Prior to ACA implementation, adults aged 19 to 25 had the highest uninsurance rates,¹⁹⁰ and the ACA offered the ability to obtain public or private insurance, or remain on their parents' private insurance through the dependent coverage provision. Despite health insurance gains for the youngest adults, we found that there was no difference in the Medicaid expansion benefit for this age group, which might indicate that uninsurance for young adult kidney transplant candidates prior to ACA implementation was not disparate. Alternatively, it might suggest that significant barriers to insurance and waitlisting remain despite multiple pathways to insurance.

Our study is not without limitations. Patients accessing care pre- and post-Medicaid expansion and in Medicaid expansion and non-Medicaid expansion states could be fundamentally different in regard to waitlisting candidacy, and these differentiating patient characteristics could be unmeasured. Provider characteristics are unmeasured, and provider characteristics, such as perceptions and behavior are associated with waitlisting.¹⁸⁵ Given that incident ESRD decreased by 1.8% in Medicaid expansion states,¹⁹¹ our finding of increased waitlist registrations following Medicaid expansion is likely an underestimate of the policy's benefit. We are unable to determine whether a waitlist registrant is a new or returning enrollee, which is important because insurance expansion differentially affects the healthcare utilization of new versus returning enrollees.¹⁹² It is possible that the use of ZCTA to impute median household income introduced bias due to spatio-temporal mismatch and/or large population sizes per geographic units. For example, we found that registrants in the highest median household income quartile experienced increases in Medicaid insurance, indicating that these registrants met Medicaid's income eligibility criteria, potentially representing misclassification. Notwithstanding, we have used the best available data at a national level to evaluate how Medicaid expansion affected kidney transplantation.

Our results are important given recent ACA policy modifications that have reversed health insurance coverage gains and resulted in the highest uninsurance rates since 2015, especially among adults who are low-income and/or living in non-expansion states.¹⁹³ Chronic kidney disease and ESRD are associated with poverty.¹⁹⁴ Increases in uninsurance among racial minority and low-income adults will likely exacerbate health disparities among sociodemographic groups that share a disproportionate burden of kidney disease, and experience referral and waitlisting barriers.

In this study using national, transplant registry data, we found that while financial needs-based health insurance increased kidney transplant registrations, increases were differential across sociodemographic groups. The lowest income adults and some racial minorities likely face unique and/or disproportionate barriers to kidney transplant waitlisting despite health insurance availability.

Table 1. Characteristics of Waitlist Candidates according to State Residence

	Medicaid Expansion states (N=155,754)		Non-Medicaid Expansion states (N=93,151)	p-value
Date of Expansion (M/Y)	1/2014 (N=127,255)	4/2014-7/2016 (N=28,499)		
Insurance, No. (%)				<0.001
Private	56070 (51.2)	12810 (53.2)	38053 (47.2)	
Medicaid	14150 (12.9)	2232 (9.3)	3681 (4.6)	
Medicare (<65 years)	36661 (33.5)	8591 (35.7)	36356 (45.1)	
Other governmental	2529 (2.3)	439 (1.8)	2494 (3.1)	
Age (years), No. (%)				<0.001
18-26	5406 (4.2)	1189 (4.2)	4134 (4.4)	
27-39	17061 (13.4)	3678 (12.9)	13469 (14.5)	
40-49	24365 (19.1)	5464 (19.2)	19888 (21.4)	
50-64	55756 (43.8)	12326 (43.3)	39520 (42.4)	
≥65	24667 (19.4)	5842 (20.5)	16140 (17.3)	
Female sex, No. (%)	47949 (37.7)	10950 (38.4)	36194 (38.9)	<0.001
Race, No. (%)				<0.001
White	53694 (42.2)	16932 (59.4)	38815 (41.7)	
Black	29372 (23.1)	9031 (31.7)	33819 (36.3)	
Hispanic/Latino	26992 (21.2)	1261 (4.4)	15445 (16.6)	
Asian	14228 (11.2)	904 (3.2)	3485 (3.7)	
Other	2969 (2.3)	371 (1.3)	1587 (1.7)	
Median household income quartile*, No. (%)				<0.001
Q1: \$7,333-41,906	18879 (18.7)	6814 (29.7)	23317 (32.3)	
Q2: \$41,912-54,297	21903 (21.7)	6714 (29.2)	20365 (28.2)	
Q3: \$54,298-72,212	26978 (26.8)	5745 (25.0)	16265 (22.5)	
Q4: \$72,216-\$250,001	33062 (32.8)	3694 (16.1)	12230 (16.9)	

*May not reflect column totals.
IQR, interquartile range.

Table 2. State-level Waitlist Trends Medicaid and non-Medicaid Expansion States
according to Insurance Type and Race

Race	Incidence Rate Ratio		
	Change per year in non-Medicaid Expansion states (2012-2018)	First year of Medicaid Expansion	Past the first year of Medicaid Expansion
<u>White</u>			
Private	1.01 (1.00-1.01)	0.94 (0.93-0.95)	0.95 (0.94-0.96)
Medicaid	0.99 (0.98-1.00)	1.12 (1.03-1.22)	1.55 (1.42-1.69)
Medicare (<65 years)	0.98 (0.98-0.99)	0.94 (0.92-0.96)	0.89 (0.87-0.91)
<u>Black</u>			
Private	1.02 (1.01-1.02)	0.98 (0.96-1.00)	0.88 (0.86-0.90)
Medicaid	0.98 (0.97-0.99)	1.08 (1.02-1.14)	1.26 (1.19-1.33)
Medicare (<65 years)	1.01 (1.01-1.02)	0.92 (0.90-0.94)	0.78 (0.76-0.79)
<u>Hispanic/Latino</u>			
Private	1.07 (1.06-1.07)	0.90 (0.89-0.92)	0.86 (0.84-0.87)
Medicaid	1.04 (1.04-1.05)	1.15 (1.12-1.19)	1.31 (1.27-1.35)
Medicare (<65 years)	1.00 (0.99-1.00)	0.95 (0.93-0.96)	0.87 (0.85-0.88)
<u>Asian</u>			
Private	1.06 (1.05-1.07)	0.92 (0.89-0.94)	0.82 (0.79-0.84)
Medicaid	1.07 (1.06-1.09)	1.19 (1.11-1.28)	1.10 (1.03-1.17)
Medicare (<65 years)	1.02 (1.01-1.02)	0.92 (0.88-0.96)	0.90 (0.86-0.94)
<u>Other</u>			
Private	1.05 (1.03-1.07)	0.75 (0.65-0.87)	1.05 (0.94-1.18)
Medicaid	1.07 (1.01-1.12)	1.22 (0.90-1.65)	1.13 (0.85-1.51)
Medicare (<65 years)	1.04 (1.02-1.07)	0.87 (0.76-1.00)	0.82 (0.72-0.93)

Table 3. State-level Waitlist Trends Medicaid and non-Medicaid Expansion States
according to Insurance Type and Median Household Income.

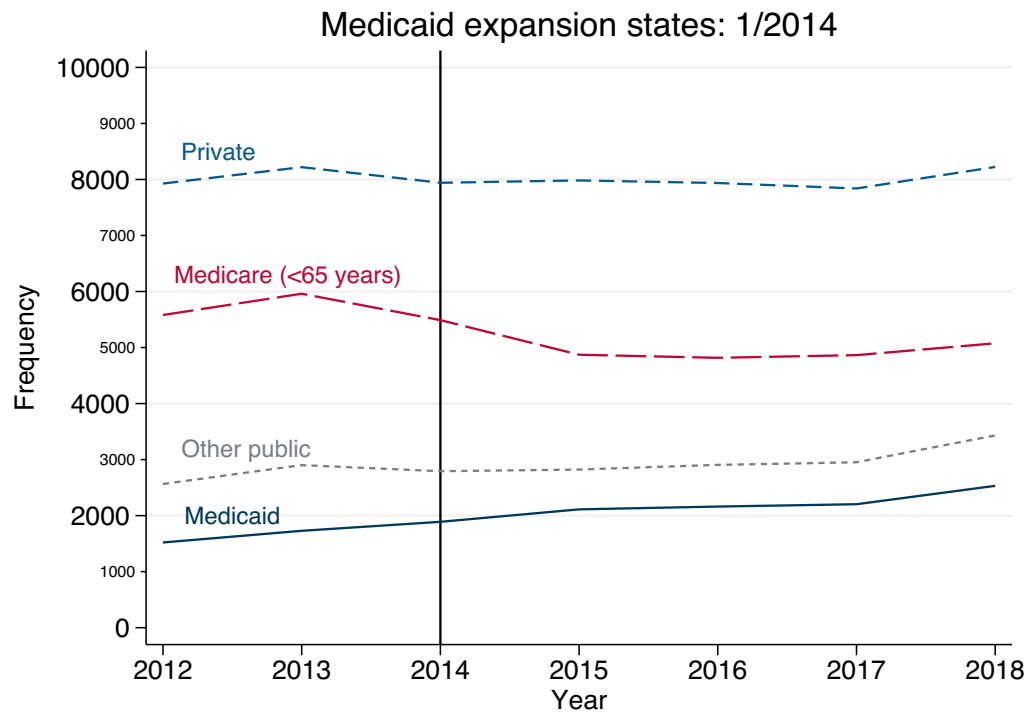
Income Quartile	Incidence Rate Ratio		
	Change per year in non-Medicaid Expansion states (2012-2017)	First year of Medicaid Expansion	Past the first year of Medicaid Expansion
Q1: \$7,333-41,906			
Private	0.91 (0.90-0.92)	1.01 (0.98-1.03)	0.77 (0.75-0.80)
Medicaid	0.94 (0.92-0.95)	1.16 (1.10-1.23)	1.05 (0.99-1.12)
Medicare (<65 years)	0.88 (0.88-0.89)	1.03 (1.01-1.06)	0.82 (0.79-0.85)
Q2: \$41,912-54,297			
Private	1.01 (1.00-1.01)	0.95 (0.93-0.97)	0.77 (0.75-0.79)
Medicaid	1.01 (1.00-1.02)	1.14 (1.08-1.21)	1.17 (1.10-1.24)
Medicare (<65 years)	1.00 (1.00-1.01)	0.88 (0.86-0.90)	0.76 (0.74-0.78)
Q3: \$54,298-72,212			
Private	1.05 (1.04-1.05)	0.95 (0.93-0.97)	0.87 (0.85-0.88)
Medicaid	1.04 (1.03-1.06)	1.25 (1.18-1.32)	1.52 (1.43-1.63)
Medicare (<65 years)	1.04 (1.03-1.04)	0.98 (0.96-1.00)	0.88 (0.86-0.91)
Q4: \$72,216-\$250,001			
Private	1.08 (1.08-1.09)	0.90 (0.89-0.91)	1.07 (1.06-1.08)
Medicaid	1.08 (1.06-1.10)	1.11 (1.04-1.19)	1.92 (1.75-2.12)
Medicare (<65 years)	1.06 (1.06-1.07)	0.97 (0.94-1.00)	1.11 (1.08-1.14)

Table 4. State-level Waitlist Trends in Medicaid and non-Medicaid Expansion States
according to Insurance Type and Age

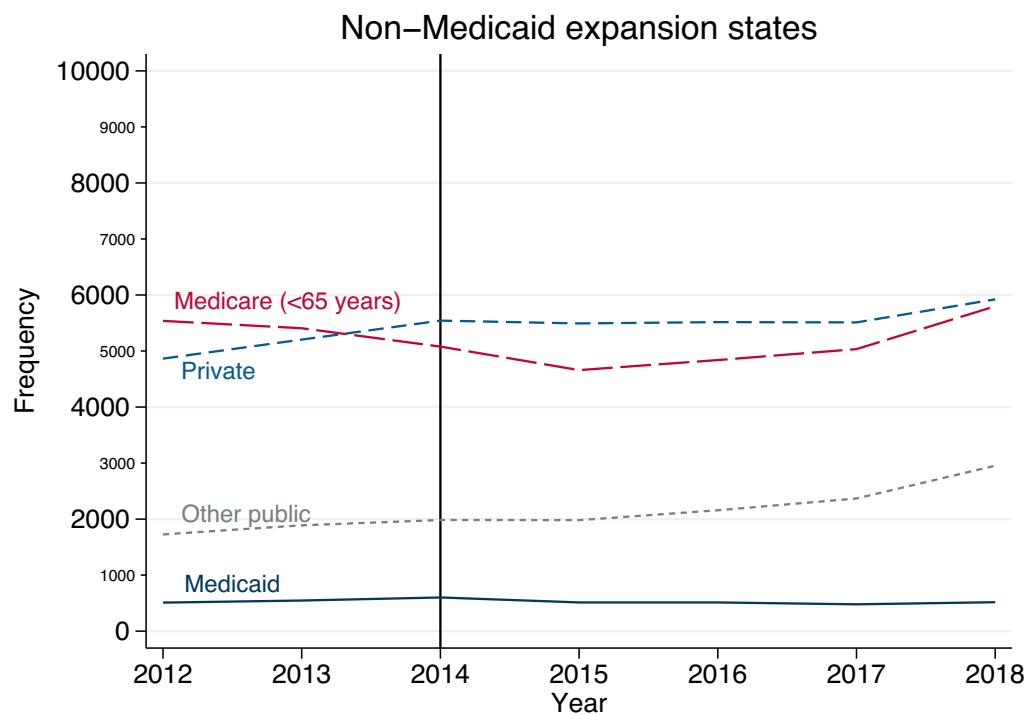
Age (years)	Incidence Rate Ratio		
	Change per year in non-Medicaid Expansion states (2012-2018)	First year of Medicaid Expansion	Past the first year of Medicaid Expansion
18-26			
Private	1.01 (1.00-1.02)	0.95 (0.88-1.02)	0.92 (0.87-0.99)
Medicaid	0.97 (0.95-1.00)	1.37 (1.21-1.55)	1.41 (1.24-1.60)
Medicare (<65 years)	0.95 (0.93-0.97)	0.89 (0.82-0.98)	0.79 (0.71-0.87)
27-39			
Private	1.04 (1.04-1.05)	0.95 (0.93-0.98)	0.96 (0.94-0.98)
Medicaid	1.01 (1.00-1.02)	1.14 (1.08-1.21)	1.38 (1.30-1.47)
Medicare (<65 years)	0.99 (0.98-0.99)	0.89 (0.87-0.92)	0.92 (0.89-0.95)
40-49			
Private	1.02 (1.02-1.03)	0.96 (0.94-0.98)	0.90 (0.88-0.92)
Medicaid	1.02 (1.01-1.03)	1.13 (1.06-1.20)	1.24 (1.17-1.32)
Medicare (<65 years)	1.00 (1.00-1.00)	0.99 (0.97-1.01)	0.81 (0.79-0.83)
50-64			
Private	1.02 (1.01-1.02)	0.94 (0.93-0.95)	0.91 (0.90-0.92)
Medicaid	1.02 (1.01-1.03)	1.15 (1.11-1.20)	1.41 (1.35-1.47)
Medicare (<65 years)	1.01 (1.01-1.01)	0.92 (0.91-0.93)	0.83 (0.82-0.84)
≥65			
Private	1.02 (1.02-1.03)	0.88 (0.84-0.91)	0.86 (0.83-0.89)
Medicaid	1.05 (1.02-1.08)	0.75 (0.62-0.90)	1.04 (0.90-1.21)

Figure 1. Frequency of Waitlist Registrations according to Insurance Type in Medicaid and non-Medicaid Expansion States

A



B



Chapter 5. Act Justly and Approach Humbly: minority trainee's perspective of learning to study race in the surgical sciences

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Keywords: race, racism, social epidemiology, surgical research, peer review, academic surgery

Running title: Act justly and approach humbly

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MINI-ABSTRACT

Recently, surgeon scientists have started to grapple with structural racism's effect on health and prior academic failures in codifying and promoting institutionalized racism in research and clinical practice. In this *Surgical Perspective*, we hope to describe our journey of being humbled by the vast work of social epidemiologists on racism and health, and we will offer our reflections on how to apply this work to future research and practice.

Racism is a public health crisis and a social determinant of health and prosperity in our racialized society.^{6,195} In the midst of this crisis, surgeon scientists have begun to grapple with structural racism's effect on health and prior failures in codifying and promoting institutionalized racism in research and clinical practice. As surgical trainees from minority backgrounds, we were motivated by *Annals of Surgery* Editorial Staff's call to promote "equity and social justice in our workforce and in surgical care". In this *Surgical Perspective*, we hope to describe our journey of being humbled by the vast work of social epidemiologists on racism and health, and we will offer our reflections on how to apply this work to future research and practice.

Our orientation towards the study of racism and health is not a minority given right, but one that we have cultivated by standing on the shoulders of our predecessors,¹⁹⁶ such as sociologist W.E.B. Du Bois and surgeons Alexa Candy, Claude Organ, Charles Drew, Levi Watkins and LaSalle Lefall, who have devoted their careers, scholarship, and lives to advancing medicine and minority health. Specifically, we orient our understanding of the association between racism and health in Fundamental Cause Theory, which describes how some disease causes, such as socioeconomic status, dictate access to resources (i.e. knowledge, power, prestige) that can be leveraged to avoid or mitigate disease.⁶ We also align ourselves with the definition of race as a social construct—in our race-conscious society—that determines daily life experiences and life chances.¹⁶ Moreover, patients are not simply biologic or genetic objects, but rather social beings nested in environments and whose conditions are embodied.¹⁴ Embodiment is how our patients incorporate and express their material and social world biologically. Failure to recognize race as a social construct and promoting race as simply inherent, biologic, anatomic, or genetic is harmful and can place individual responsibility on minorities

rather than on healthcare system or the modifiable social conditions within which these individuals exist.

Recently, routinely applied clinical prediction models incorporating race have been found to direct care and resources to white patients rather than racial minorities, potentially exacerbating racial disparities. For example, some of these models may deem racial minorities too high risk for cardiac surgery or assign different kidney function estimates to racial minorities potentially affecting specialist referral or listing for kidney transplant—in part based on a flawed biological interpretation of a social construct: race.¹⁹⁷ In these types of algorithms, what race represents (i.e. social construct, biology, genetics) is undefined. While prediction models should be used to assess risk and guide clinical decisions, they cannot be used in good faith if we do not consider the historical context within which they were developed, the biases of their developers, or the social determinants that explain differences in health outcomes according to race.

Let us not forget that we, too, as surgical trainees of color have been humbled after learning about social epidemiologic discourse and theory. We are now aware of our own naïve and problematic use of race in statistical models and interpretations of racial disparities in surgical research. We are not alone.

So, what do we hope for our futures as surgeon scientists in the academy?

Social epidemiologic theory should drive racial disparities research

Social epidemiology is a branch of epidemiology that specifically examines social determinant influences on rates and distribution of morbidity and mortality. Social epidemiologic theories (e.g., Fundamental Cause, Eco-Social, Psychosocial, Political Economy of Health) should be leveraged to describe observed associations between social determinants and health outcomes because theory is a tool for organizing relationships and explaining observations. Racial disparities research without anti-racism vocabulary, standard race-conscious definitions, and social epidemiologic theory is harmful because it leads to inaccurate statistical modeling and subsequent inference. Race is a covariate modeled along with other covariates, such as age, sex, comorbidities and laboratory values. Yet, investigators rarely explicitly define race. In our race-conscious society, race is resilient—there will almost always be a difference in health outcomes according to race, an association between race and a health outcome, or a difference in risk magnitude according to race. The problem, and where one's own novice and implicit biases emerge, is in how these racial findings are interpreted. In other words, statistical models hastily incorporating race and not using social epidemiologic theory results in racialized interpretations.¹¹ Racialized interpretations perpetuate beliefs that the social construct of race determines biology, genetics and anatomy: an oxymoron. We align ourselves with other authors who have suggested that it be standard to explain why race is included as a statistical model covariate and defend modeling choice (i.e. stratification, interaction term) in a manuscript methods section.¹⁹⁸ A corollary can be found in qualitative research where it is standard to report theoretical and conceptual frameworks, philosophical assumptions, and reflexivity statements. In this *Perspective*, we too have reported our orientation to Fundamental Cause Theory and stated and cited race conceptualizations to which we prescribe.

We should also leverage Critical Race Theory and Public Health Critical Race praxis to assess our research aims, approach and subsequent interpretations of reported racial disparities.¹⁹⁹ Examples of this practice as surgeon scientists would be to question the question, examine our own implicit biases and assumptions during study design, be critical of where our knowledge comes from, examine the power differentials within our research groups, and be mindful of how our scholarship and subsequent advancement in the academy honor and incorporate the voices and bodies of the communities that we study.

Methodologies should move beyond just describing racial differences to mechanistic understanding

Methodological approaches, such as mediation and decomposition analysis, multilevel modeling, agent-based modeling, natural experiments, instrumental variable analysis, and mixed methods research are useful in explaining contextual and structural contributions to racial disparities. Race, as a fundamental cause of disease, affects health outcomes through mediators (e.g., discrimination, housing, employment), and mediation and decomposition analysis aims to determine how much of a racial disparity can be eliminated by intervening on modifiable mediators.²⁰⁰ Similarly, many contextual factors can *only* be understood through robust, qualitative research. Constructivist and subjectivist epistemological perspectives permit multiple views of the “truth” and can reduce the likelihood of false interpretations or claims of objective truth regarding the influence of racism on health. For us as research fellows, this has required us to go beyond a standard, routinely prescribed curriculum and take advanced epidemiology and qualitative research courses.

Similarly, administrative databases and registries could strive to include covariates for which race is often assumed to be a surrogate (e.g., socioeconomic indicators, health behavior). These efforts would strengthen databases and better contextualize clinical data without relying on race as proxy or as a crux. In our work, we have found that to study contextual and structural factors not routinely collected in national registries and administrative databases, novel linkages and imperfect imputations have to be performed. A theoretical, practical and financial commitment to improving registries and databases is imperative to advancing racial disparities research.

Peer review should involve a surgeon scientist with social epidemiology expertise

Peer review is a process intended to provide expert critical feedback specific to study aims, methodologies, and conclusions, and it should serve as a gatekeeper for inaccurate and harmful science. Public Health Critical Race praxis calls for a decentering of the academy, which would mean that we become more mindful of our gatekeepers' characteristics and the potential policing of viewpoints that challenge the status quo. It is time that we recognize racial disparities research as a rigorous science deserving of expert contribution and review—similar to what would be expected for complex methodologies like machine learning and robust sensitivity analyses. It is not transparent whether journals routinely require this expertise to review manuscripts on racial disparities or statistical models incorporating race. A stated commitment from journals to do so would be a step in the right direction.

As surgeon scientists, we will need to continually revisit and refine our beliefs, perceptions and attitudes on racism and health. At some point, many of us have negatively contributed to promoting racism in the surgical literature. Enhancing our research quality will require the commitment of surgeon scientists, journals, reviewers and the academy at large. As minorities, this work is deeply personal. The current sociopolitical climate has ignited our commitment to our communities, and we hope that our peers will take this humble journey to better science with us. Perhaps, if we truly care about addressing the public health crisis of racism, we can humble ourselves to the science and study of racism and health and learn theory and methodologies that will produce research to improve the health of racial minorities.

Chapter 6. Conclusion

In this dissertation, we have examined racial and socioeconomic differences in organ donation and access to transplantation. We found that racial disparities in deceased organ donation have attenuated over time, that there are socioeconomic status differences according to race and biologic relationship to the recipient in the living kidney donor population, and that financial needs-based health insurance programs still leave racial minority and low-income adults with decreased access to kidney transplantation.

Our results challenge commonly held beliefs around from who deceased donor organs are recovered, highlight how racial differences in both donation rates and living kidney donor outcomes have potentially been subject to racialized interpretations, and demonstrate how the use of social epidemiologic theory allows for alternate explanations and questions regarding observed racial differences. For this dissertation, we have leveraged public health data sources, which for the main covariates of interest “race” and “socioeconomic status” present limitations. However, central to our methodological choices and interpretation of results is social epidemiologic theory and we believe that use of social epidemiologic theory has allowed us to overcome some of the inherent limitations of these data sources. Our findings regarding the influence of Medicaid expansion are also consistent with what we know about the need for multi-level interventions for addressing health inequalities.²⁰¹

Moving forward, more data are needed to sufficiently understand and address racial and socioeconomic differences in organ donation and access to transplantation. Immediately achievable changes that will advance the science include acknowledging race as a social construct, disapproving of the use of race as proxy for biology or genetics, and

measuring genetic, health behavior, and cultural factors if they are the core of research hypotheses. We would also recommend that donor, candidate, and recipient residential address be geocoded, linked to census-based data products, and made available in national, transplant registry data. While we have performed descriptive social epidemiology, we encourage a consequentialist approach whereby methodological tools are leveraged to maximize goals of caring for individuals who are disenfranchised by the social hierarchy in the United States.^{202,203}

Before considering consequentialist epidemiologic approaches like simulations or randomized controlled trials, we should consider the following descriptive, future directions:

- How have donation rates according to socioeconomic status and its dimensions changed over time in the United States? Does structural racism mediate the relationship between race and organ donation?
- Are socioeconomic status and its individual dimensions associated with incident end-stage renal disease after living kidney donation? Does socioeconomic status or its individual dimensions mediate the relationship between race and incident end-stage renal disease after living kidney donation? Among individual who have Apolipoprotein L1 high-risk genotypes, does socioeconomic status or its dimensions moderate its relationship with kidney function decline among living kidney donors?
- What are the barriers and facilitators presented in the donor and candidate evaluation process that affect waitlisting of insured racial minority and low-income adults?

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197. Vyas DA, Eisenstein LG, Jones DS. Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms. *New England Journal of Medicine*. 2020.
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199. Ford CL, Airhihenbuwa CO. The public health critical race methodology: praxis for antiracism research. *Soc Sci Med*. 2010;71(8):1390-1398.
200. Jackson JW, VanderWeele TJ. Decomposition Analysis to Identify Intervention Targets for Reducing Disparities. *Epidemiology*. 2018;29(6):825-835.
201. Achieving Health Equity: Closing The Gaps In Health Care Disparities, Interventions, And Research. *Health Affairs*. 2016;35(8):1410-1415.
202. Galea S. An argument for a consequentialist epidemiology. *Am J Epidemiol*. 2013;178(8):1185-1191.
203. Nandi A, Harper S. How Consequential Is Social Epidemiology? A Review of Recent Evidence. *Current Epidemiology Reports*. 2015;2(1):61-70.

CURRICULUM VITAE - Amber Bradlyn Kernodle, MD MPH

PERSONAL INFORMATION

Date and Location of Birth:

November 6, 1987

Tacoma, Washington

Mailing Address:

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Baltimore, Maryland

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EDUCATION

Johns Hopkins University , Baltimore, Maryland Bloomberg School of Public Health, PhD Candidate in Clinical Investigation	2018-present
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Johns Hopkins University , Baltimore, Maryland School of Medicine, Halsted General Surgery Resident	2015-present
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University of North Carolina , Chapel Hill, NC School of Medicine, Doctor of Medicine	2010-2015
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University of North Carolina , Chapel Hill, NC Gillings School of Global Public Health, Master of Public Health	2013-2014
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University of North Carolina , Chapel Hill, NC Department of Chemistry, Bachelor of Arts in Chemistry, Minor in Biology Department of Romance Languages, Bachelor of Arts in Spanish	2010-2014
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CLINICAL/HOSPITAL APPOINTMENTS

Resident Physician in General Surgery	Johns Hopkins Hospital	2015-present
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LICENSURE

Physician and Surgeon (Lic. No. D0085688), Maryland Board of Physicians	2018
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PROFESSIONAL CERTIFICATIONS AND OTHER TRAINING

<i>Graduate Certificate in Health Disparities and Health Inequality</i> , Johns Hopkins Bloomberg School of Public Health	2018-present
<i>Fundamental of Laparoscopic Surgery</i> , Society of American Gastrointestinal and Endoscopic Surgeons	2018
<i>Advanced Trauma Life Support</i> , American College of Surgeons	2015
<i>Advanced Cardiovascular Life Support</i> , American Heart Association	2015
<i>Basic Life Support Provider</i> , American Heart Association	2015

MEMBERSHIPS AND PROFESSIONAL AFFILIATIONS

Association for Surgical Education , Resident Member	2021
Surgical Outcomes Club , Trainee Member	2020
Association for Academic Surgery , Candidate Member	2019
Vascular and Endovascular Society , Candidate Member	2019
Society of Vascular Surgery , General Surgery Resident	2018
American College of Surgeons	2015
John B. Graham Medical Student Research Society , University of North Carolina School of Medicine	2014
Eugene S. Mayer Honor Society for Community Service , University of North Carolina School of Medicine	2011

ACADEMIC AWARDS AND HONORS

Distinguished Medical Student Teaching Society , Johns Hopkins University School of Medicine	2017
Diversity Scholarship Travel Grant for Eastern Vascular Society 31st Annual Meeting	2017

11th Annual Introduction to Academic Vascular Surgery Conference	2017
American Medical Women's Association Glasgow-Rubin Commendation for Academic Achievement	2015
Merck Manual Award	2015
Alpha Omega Alpha Honor Medical Society	2014
Medical Alumni Loyalty Fund Scholarship University of North Carolina School of Medicine	2014
Kerr L. White and Edward H. Wagner Scholarship in Health Care Research UNC Gillings School of Global Public Health	2013

TEACHING AND MENTORING ACTIVITIES

<i>Facilitator</i> , Provider Awareness Cultural Dexterity Toolkit for Surgeons Curriculum Johns Hopkins Hospital, Baltimore, MD.	2021
<i>Attendee</i> , Institute for Excellence in Education Summer Teaching Camp Johns Hopkins Hospital, Baltimore, MD.	2020
<i>Halsted Teaching Resident</i> , Medical Student Surgery Clerkship Johns Hopkins University School of Medicine, Baltimore, MD.	2019
<i>Resident Preceptor</i> , Transition to Residency and Internship and Preparation for Life Capstone Course Johns Hopkins University School of Medicine, Baltimore, MD.	2019
<i>Resident Preceptor</i> , General Surgery Intern Skills Lab Johns Hopkins Hospital, Baltimore, MD.	2018
<i>Resident Preceptor</i> , Objective Structured Assessment for Technical Skills for Interns Johns Hopkins Hospital, Baltimore, MD.	2018
<i>Resident Preceptor</i> , Medical Student Transition to Wards Series Johns Hopkins University School of Medicine, Baltimore, MD.	2017

OTHER SERVICE ACTIVITIES

Johns Hopkins Hospital General Surgery Residency Program Admissions

Committee, Baltimore, MD.

Member

Johns Hopkins Hospital Surgical Critical Care Fellowship Program Admissions

Committee, Baltimore, MD.

Member

Johns Hopkins Hospital Housestaff Diversity Council, Baltimore, MD.

Treasurer

Johns Hopkins Hospital Quality Improvement Surgical Sepsis Workgroup,

Baltimore, MD.

Resident Representative

FUNDING

Ruth L. Kirschstein Research Service
Award (NRSA) Individual Postdoctoral
Fellowship (F32)

Amber Kernodle (PI)
Dorry Segev (Primary
mentor)

2018 – Present

Project Narrative: Each year in the US, the 6000+ healthy individuals who donate a kidney to a loved one, friend or stranger amounting to a total of 142,111 individuals who have donated since 1988, will experience a 25-40% decline in renal function, which increases their risk for chronic kidney disease (CKD) and end-stage renal disease (ESRD). Recent evidence suggests that Black living kidney donors are at an even higher risk of these long-term morbidities than White donors, and while compelling evidence points to genetic risk factors as key drivers of the disparity, the relative contribution of socioeconomic status (SES) and environmental context is unknown. The goal of the proposed research project is to better understand the impact of socioeconomic status and local environment characteristics on post-donation CKD/ESRD, which will be immediately clinically applicable as it will (1) inform personalized follow-up care plans based on donor social circumstances, and (2) prevent exclusion of disadvantaged populations from national-based monitoring interventions.

Institute for Excellence in Education

Pamela Lipsett (PI)
Amber Kernodle (co-
PI)

2020 – Present

Project Narrative: Many patients admitted to the hospital after incident violent trauma (i.e., assaults, gunshot wounds or stabbings) are socially disadvantaged. While social

determinant curricula are increasing in medical education, only 41% consider it high priority. Therefore, interns often enter training programs underprepared to provide socially competent care to this vulnerable population. The overarching objective is to implement a pilot educational intervention that leverages narrative medicine and critical reflection to teach Baltimore-specific social context to surgical interns. We will video-record semi-structured interviews with patients admitted to Johns Hopkins Hospital following violent trauma. These educational videos will be shown to surgical interns as the study intervention. To evaluate the interview content, we will apply eco-social theory in deductive reasoning approach. To evaluate the effect of the intervention on surgical interns, we will use grounded theory analyses of critical reflections, and validated rubric for measuring reflective capacity. Results from the study will inform social determinant curricula in clinical settings and at the graduate medical education level.

PEER REVIEWED PUBLICATIONS

1. Kernodle AB, Ishaque T, Motther JD, Jackson KR, Chiang P, Gestin S, Boyarsky B, Garonzik-Wang J, Gentry S, Segev DL, Massie AB. MELD is MELD is MELD? Transplant Center-Level Variation in Waitlist Mortality for Candidates with the Same Biologic MELD. *Am J Transplant*. [In Press]
2. Usoro A, Hirpa M, Daniel M, Harris V, Ware A, Kernodle AB, Elliott T, Piggott DA, Bienstock JL. Promoting Diversity, Equity, and Inclusion: Building Community for Underrepresented in Medicine Graduate Medical Education Trainees. *J Grad Med Educ*. 2021;13(1):33-36.
3. Maredia H, Bowring MG, Massie AB, Bae S, Kernodle AB, Oyetunji S, Merlo C, Higgins RSD, Segev DL, Bush EL. Better Understanding the Disparity Associated With Black Race in Heart Transplant Outcomes: A National Registry Analysis. *Circ Heart Fail*. 2021;14(2): e006107.
4. Kernodle AB, Zhang W, Motter JD, Doby B, Liyanage L, Garonzik-Wang J, Jackson KR, Boyarsky BJ, Massie AB, Purnell TS, Segev DL. Examination of Racial and Ethnic Differences in Deceased Organ Donation Ratio Over Time in the US. *JAMA Surg*. 2021: e207083.
5. Karami F, Kernodle AB, Ishaque T, Segev DL, Gentry SE. Allocating kidneys in optimized heterogeneous circles. *Am J Transplant*. 2021;21(3):1179-1185.
6. Jackson KR, Motter JD, Bae S, Kernodle AB, Long JJ, Werbel W, Avery R, Durand C, Massie AB, Desai N, Garonzik-Wang J, Segev DL. Characterizing the landscape and impact of infections following kidney transplantation. *Am J Transplant*. 2021;21(1):198-207.

7. Kernodle AB, Enumah ZO. Act Justly and Approach Humbly: Minority Trainees' Perspective on Learning to Study Race in the Surgical Sciences. *Ann Surg*. 2021;273(4):e127-e128.
8. Wood NL, Kernodle AB, Hartley AJ, Segev DL, Gentry SE. Heterogeneous circles for liver allocation. *Hepatology*. 2020.
9. Strauss AT, Boyarsky BJ, Garonzik-Wang JM, Werbel W, Durand CM, Avery RK, Jackson KR, Kernodle AB, Baker T, Snyder J, Segev DL, Massie AB. Liver transplantation in the United States during the COVID-19 pandemic: National and center-level responses. *Am J Transplant*. 2020.
10. Siegel N, DiBrito S, Ishaque T, Kernodle AB, Cameron A, Segev D, Adrales G, Garonzik-Wang J. Open inguinal hernia repair outcomes in liver transplant recipients versus patients with cirrhosis. *Hernia*. 2020.
11. Jackson KR, Motter JD, Kernodle AB, Desai N, Thomas AG, Massie AB, Garonzik-Wang JM, Segev DL. How do highly sensitized patients get kidney transplants in the United States? Trends over the last decade. *Am J Transplant*. 2020.
12. Jackson KR, Bowring MG, Kernodle AB, Boyarsky B, Desai N, Charnaya O, Garonzik-Wang J, Massie AB, Segev DL. Changes in offer and acceptance patterns for pediatric kidney transplant candidates under the new Kidney Allocation System. *Am J Transplant*. 2020.
13. Boyarsky BJ, Werbel WA, Durand CM, Avery RK, Jackson KR, Kernodle AB, Snyder J, Hirose R, Massie IM, Garonzik-Wang JM, Segev DL, Massie AB. Early national and center-level changes to kidney transplantation in the United States during the COVID-19 epidemic. *Am J Transplant*. 2020;20(11):3131-3139.
14. Boyarsky BJ, Ruck JM, Chiang TP, Werbel WA, Strauss AT, Getsin SN, Jackson KR, Kernodle AB, Van Pilsum Rasmussen SE, Baker TB, Al Ammary F, Durand CM, Avery RK, Massie AB, Segev DL, Garonzik-Wang JM. Evolving Impact of COVID-19 on Transplant Center Practices and Policies in the United States. *Clin Transplant*. 2020;34(12):e14086.
15. Boyarsky BJ, Po-Yu Chiang T, Werbel WA, Durand CM, Avery RK, Getsin SN, Jackson KR, Kernodle AB, Van Pilsum Rasmussen SE, Massie AB, Segev DL, Garonzik-Wang JM. Early impact of COVID-19 on transplant center practices and policies in the United States. *Am J Transplant*. 2020;20(7):1809-1818.
16. Boyarsky BJ, Massie AB, Love AD, Werbel WA, Durand CM, Avery RK, Jackson KR, Kernodle AB, Thomas AG, Ronin M, Altrich M, Niles P, Trahan C, Hewlett J,

- Segev DL, Garonzik-Wang JM. Early Experiences With COVID-19 Testing in Transplantation. *Transplant Direct*. 2020;6(7):e572.
17. Boyarsky BJ, Jackson KR, Kernodle AB, Sakran JV, Garonzik-Wang JM, Segev DL, Ottmann SE. Estimating the potential pool of uncontrolled DCD donors in the United States. *Am J Transplant*. 2020;20(10):2842-2846.
 18. Boyarsky BJ, Chiang TP, Werbel WA, Durand CM, Avery RK, Getsin SN, Jackson KR, Kernodle AB, Van Pilsum Rasmussen SE, Massie AB, Segev DL, Garonzik-Wang JM. Early Impact of COVID-19 on Transplant Center Practices and Policies in the United States. *Am J Transplant*. 2020.
 19. Jackson KR, Zhou S, Ruck J, Massie AB, Holscher C, Kernodle AB, Glorioso J, Motter J, Neu A, Desai N, Segev DL, Garonzik-Wang J. Pediatric deceased donor kidney transplant outcomes under the Kidney Allocation System. *Am J Transplant*. 2019;19(11):3079-3086.
 20. Hicks CW, Wang P, Kernodle AB, Lum YW, Black JH, 3rd, Makary MA. Assessment of Use of Arteriovenous Graft vs Arteriovenous Fistula for First-time Permanent Hemodialysis Access. *JAMA Surg*. 2019.
 21. Wang S, Kernodle AB, Hicks CW, Black JH, 3rd. Endovascular repair of tortuous recurrent femoral-popliteal aneurysm in a patient with Loeys-Dietz syndrome. *J Vasc Surg Cases Innov Tech*. 2018;4(2):156-159.
 22. Arhuidese I, Kernodle AB, Nejim B, Locham S, Hicks C, Malas MB. Sex-based outcomes of lower extremity bypass surgery in hemodialysis patients. *J Vasc Surg*. 2018;68(1):153-160.
 23. Hicks CW, Kernodle AB, Abularrage CJ, Heller JA. A national resident survey about the current state of venous education in vascular surgery training programs. *J Vasc Surg Venous Lymphat Disord*. 2017;5(6):897-904.e892.
 24. Clark LH, Ko EM, Kernodle AB, Harris A, Moore DT, Gehrig PA, Bae-Jump V. Endometrial Cancer Survivors' Perceptions of Provider Obesity Counseling and Attempted Behavior Change: Are We Seizing the Moment? *Int J Gynecol Cancer*. 2016;26(2):318-324.
 25. Staley A, Kernodle AB, Chuang A. Tell a Meaningful Story: Qualitative Analysis of Obstetrics and Gynecology Clerkship Narratives. *Obstetrics & Gynecology*. 2015; 126:52S.
 26. Kernodle AB. Mammographic Breast Density as a Predictive Tool in Average-risk Women aged 40 to 59: a systematic review. 2014. (Master's Paper at Gillings

School of Global Public Health, Chapel Hill, NC). Retrieved from <https://cdr.lib.unc.edu>.

BOOK CHAPTERS AND OTHER PUBLICATIONS

1. Kernodle, AB, Abularrage CJ. "Spinal Operative Exposure". *Rutherford's Vascular Surgery and Endovascular Therapy, 10th Ed*. Editors Anton P. Sidawy & Bruce Perler [In Press]
2. Kernodle, AB, Black, JH. "Endovascular Repair of Thoracic Aortic Pathology". *Johns Hopkins Textbook of Cardiothoracic Surgery, 3rd Ed*. Editor: David D. Yuh. [In Press]
3. Kernodle, AB, Hicks CW. Item writer for the This Week in SCORE Vascular – Arterial, Part 2 of 2 "New Hemodialysis Access" Quiz [In Press]
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Brief Biosketch - Amber Bradlyn Kernodle, MD MPH

Dr. Amber Bradlyn Kernodle was born in Tacoma, Washington and raised in Durham, North Carolina by her mom, Jo Cunningham. Her upbringing was greatly influenced by her grandma, Maxine Cunningham, who she spent a lot of time with in rural, North Carolina. As a child, Amber dabbled in almost every sport and extra-curricular activity to include tap, jazz, ballet, gymnastics, basketball, tennis, cross country, track and field, and competitive cheerleading. In general, she loves competitive sports (and hates to lose) and excelled in middle school basketball, cheerleading and high school track and field (long jump, triple jump and 200-meter dash specifically). At a young age, she developed interests in math and science, being selected as a “Science Star” in elementary school for special field trips (such as a sleepover at the National Air and Space Museum in Washington, DC), having a space-themed birthday party at the local Museum of Life and Science that included freeze-dried space food and performing at-home science experiments like magic rock crystal growing.

A true Tar Heel at heart, Amber applied early action and committed to the University of North Carolina at Chapel Hill instead of Duke University (a common conundrum for the North Carolinians) for her undergraduate education. At UNC-Chapel Hill, she studied Chemistry and Spanish with knowledge that she desired a career in medicine. One summer in college, Amber participated in Larry Keith’s Medical Education Development (MED) Program at UNC School of Medicine, a preparatory, pipeline program for minority and underrepresented students in medicine. Following, she attended UNC School of Medicine.

Between year three and four of medical school, she obtained a Master of Public Health at UNC Gillings School of Global Public Health. It was during this time that she developed an interest in population health and social determinants of health, and a desire to do public health research that informs social policy. To the lament of her primary care and public health mentors, she decided to pursue surgery because she was certain that it was possible to blend surgery and population health.

After medical school, Amber moved to Baltimore to train in General Surgery at the Johns Hopkins Hospital. After three years of clinical training, she enrolled in the Graduate Training Program in Clinical Investigation’s Doctoral Program. During this time, she cultivated an interest and expertise in Social Epidemiology. While working on her PhD, she became a certified yoga instructor and rekindled her wheel-throwing pottery hobby. She enjoys all things crafty, pine/cedar scents, semi-sweet vanilla lattes, red wine, a good anchovy Caesar or arugula salad, bind and heart opening yoga poses, being barefoot, white noise, the sun, the water, and her rambunctious yorkies, Bo and Bear.